

# Northumbria Research Link

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**DOES RESPITE CARE ADDRESS THE  
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SERVICE USERS AND CARERS? AN  
EXPLORATION OF THEIR  
PERSPECTIVES AND EXPERIENCE  
OF RESPITE CARE**

A.M. Wolkowski

A thesis submitted in partial fulfilment of  
the requirements of the University of  
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**ANNA MARIA WOLKOWSKI**

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Northumbria at Newcastle for the degree  
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Research undertaken in The School of  
Health and Life Sciences

July 2012

## **Abstract**

There are clear indications that over the coming years, as more people live longer with life limiting illnesses an increasing amount of support for carers of service users with palliative care needs will be required. Respite care is often described in UK policy and guidance as a key need in providing this support and yet little is known about it for patients with life limiting illnesses and there is a lack of research to support its efficacy. The purpose of this research was therefore to establish whether respite care addresses the needs of palliative care service users and carers.

The approach was qualitative and the methodology was interpretive. The method used was constructivist Grounded Theory. This provided high compatibility with the theoretical underpinnings which were learning from the experiences of service users and carers, embracing the principles of critical practise and learning through relational endeavour. Data collection was carried out by unstructured informal interview with three couples and two bereaved carers who had experienced hospice respite care. The participants were interviewed on two occasions and social network circle activity was undertaken as part of theoretical sampling.

Findings showed that respite care is valued by palliative care service users and carers although there are some fundamental tensions in service models which limit its potential. A theory of vulnerability and resilience was developed which accommodated issues of needs and acceptance, choice and risk, loss and gains.

A reframing of respite care as an empathic response within a new palliative care approach is proposed. Within this the centrality of the relationship is reinforced and the need for support over a potentially long and more uncertain illness trajectory is acknowledged. The articulation of respite care needs and the insights gained in this study have the potential to influence practice and provide a platform for innovative service development and improvement.

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And lastly, I would like to take the opportunity to thank my dear late parents Betty and Ali Wolkowski who would have been very proud.

## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contribution from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the:

- School of HCES Research Ethics Sub Committee, Northumbria University on the 13th June 2008
- Local Ethical Committee, , 12th September 2008

Name: Anna Maria Wolkowski

Signature:

Date: 4<sup>th</sup> July 2012

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## **Chapter 1 Introduction**

“Does respite care address the needs of palliative care service users and carers?

An exploration of their perspectives and experience of respite care”.

### **1.1 Introducing the doctoral journey as a learning process**

“Knowledge emerges only through invention and re- invention, from the restless, impatient, continuing, hopeful inquiry human beings pursue in the world, with the world, and with each other” (Freire, 1998, pg. 53)

I begin the introduction with this quotation by Paulo Freire (1998) as it sets the context for my “doctoral journey” (Trafford and Leshem, 2002) and it describes the mind set in which I carried out the study. “In a complex healthcare system dominated by demographic changes, medical advancement and technological breakthrough” (Yam, 2005, pg. 568), the professional doctorate provides nurses with the opportunity to develop multiple skills and knowledge to ensure that they are well placed to meet the new demands and expectations of the nursing profession associated with these developments. However, at its core the professional doctorate is about learning and being motivated to learn to the deepest level of inquiry; in this case, from the experiences of palliative care service users and carers. For Freire (1998), learning is a collaborative process of learning from each other rather than knowledge being deposited by an all-knowing teacher and as such, from the beginning, this “human” process of collaboration and “hopeful inquiry” (Freire, 1998) is fundamental to my doctoral studies and, I feel, advanced knowledge in nursing. Therefore, this description of my position captures the breadth and potential of the study at the same time as making the reader aware that it is a study that is fundamentally about learning

rather than proving and within that, there is an invitation to gain insight into the lived experiences of palliative care service users and carers in the context of their need for respite care.

## **1.2 Background and context of the study**

The central focus of the professional doctorate lies in the context of professional practice (Yam, 2005) and in keeping with this, my research emerged from my practice vision for the hospice in which I work. This was to develop a listening culture in which service users and carers were properly involved in the evaluation and development of services provided by the hospice. Learning from service users and carers is one of the theoretical underpinnings of the research but at one point, it was my intention that my research question would be *about* involving palliative care service users and carers in the evaluation and development of services. Certainly this was relevant to my practice as I had been given the responsibility of developing service user and carer involvement at the hospice. Having witnessed the positive effects its development appeared to be having on service users and carers and the positive impression our work was making at a regional and national level, I was very interested in carrying out research that explored this process. However, it was the first of two significant occasions in my journey to my research question and design that drew me towards the subject of respite care. This is recounted in a chapter that my social work colleague at the hospice had been asked to write for a book on user involvement (Hodgson, 2007). In the chapter, she describes the group work which took place at the Hospice's Listening Day for service users and carers:

“In one of the groups, the discussion got round to respite care. Or at least the discussion got round to how poor respite care facilities were in this area. The sad fact that younger patients with neurological conditions often had to go into nursing or residential accommodation for respite care where they might be surrounded by other residents twice

their age was acknowledged but with regret. Even coming into The Oaks Hospice for respite care was not always ideal as often the carer came in every day early in the morning and stayed until the evening.....Respite care does not always mean that the carer and patient need to be separated. Perhaps they need to be together but away from all the rest of their care and responsibilities.

A result of this discussion, where The Chief Executive and Chair were present, was that The Board of Trustees should look once again at the idea that we have a family respite care centre built to meet such a need.” (Hodgson, 2007, pp.180 – 181).

Already engaged by this discussion, it was in developing a business case to persuade the Board of Trustees of the benefits of respite care and the importance of investing in such a project, that I discovered that respite care for people with life limiting illnesses appeared to be something of a mystery. I discovered that little was known about respite care services for patients with a life-limiting illness (Owen and Johnson, 2005, Skilbeck et al, 2005), that there was a lack of research to support its efficacy (McNally et al, 1999, Ingleton et al, 2003) and that there was “a gap in the knowledge” about the impact of respite care on carers (Ingleton et al, 2003, pg 573). Added to this, “a basic problem of definition” (Owen and Johnson, 2005, pg 197) had been identified with no clear criteria agreed for the purpose of respite services (Payne et al, 2004). Although I was aware that there was a need for further research in user involvement in palliative care (Payne et al, 2005), I felt there was evidence that user involvement was an area that was attracting considerable interest (Cotterill and Paine, 2005, NCPC, 2004) as opposed to respite care which never seemed to make its way onto conference programmes. This highlighted that academic interest in respite care for palliative care service users and carers appeared to be limited.

From a practice perspective, the Listening Day discussion alone as described above demonstrated to me that respite care was problematic and that service user and carer experience of respite care could be poor. In keeping with the

expectations of a professional doctorate, there was certainly the potential to” improve the standard of patient care” (Yam, 2005) but more than this, I was intrigued by the fact that in just one discussion, so many issues were raised with regard to respite care including the poor quality of services, having to endure being in an inappropriate setting, being separated in order for the carer to have a rest but the carer not having a rest, the potential benefits of not being separated for respite care. It struck me that respite care was such a taken for granted concept that was often spoken about in a trite way but in this discussion, there was a hint of tension and disappointment bubbling under the surface of something that was much needed and supposedly straightforward. Having established that there were both theoretical and practice concerns regarding respite care, I increasingly felt that this was an appropriate area of research for my professional doctorate.

### **1.3 Deciding on the research question**

On establishing that my area of research would be respite care and the research topic would be respite care for service users and carers, I then had to decide on the research question. Finding a focus and pinning down a research question is often more difficult than deciding on the area of research (Illing, 2007). What I knew at this point was that there was little research about the value of respite care for palliative care service users and carers but there was a great deal of anecdotal evidence to say it was a good thing. The focus of the research needed to be on the views of service users and carers but also as respite care was bound up in the core concepts of care and need, it was important that the question reflected the desire to understand what the needs were and whether respite care met them:

“Does respite care address the needs of palliative care service users and carers?  
A study involving service users and carers in an exploration of their perspectives and experience of respite care”.

This is the first version of the question. The reader will note that this version differs from the final one as shown above in that it includes the word “involving”. This stemmed from the interpretive philosophy behind the research question which was about learning together from service users and carers rather than the more positivist position of ‘doing to’ service users and carers. I had aspirations to *involve* service users and carers in the design of the research for example and in other ways as described in the INVOLVE literature (NHS National Institute of Health Research, 2012). But although I achieved the objective of asking service users and carers to comment on the patient information leaflets I had designed, even though I felt I had recruited the service users and carers in the study as participants rather than subjects, on reflection, once into the study proper, I felt I had not done enough to enable me to use the word “involve” in its proper sense as defined by INVOLVE (NHS National Institute of Health Research, 2012). Therefore I adapted my research title accordingly and the word “involving” was taken out.

Respite care can of course refer to inpatient, day or home based care (Ingleton et al, 2003) and part of the problem with researching it is that it can mean different things to different people. Bearing in mind that it is very common for researchers at the start of a project to attempt too much and that “depth rather than breadth is what characterises a good research proposal” (Lee, 2009, pg. 70) I decided that my primary focus would be inpatient respite care. This was because of a number of reasons. First, that this would be manageable, second, that this was what the hospice provided and I would be able to explore the experience of it with service users and carers, third, in speaking to staff and service users and carers, this is



generally what they thought of as 'respite care' and last, in patient respite care, where the patient is separated from the carer, was where I felt most of the tensions lie in terms of acceptability for service users and carers, the potential medicalization of the service user and other issues as identified by service users and carers in the Hospice Listening Day discussion as described above (Hodgson, 2007). This would not preclude other types of respite care being explored in line with the wishes of the participants, and indeed it didn't, but the primary area of concern began with inpatient respite care. Having experienced one period of inpatient respite care at the hospice became part of the inclusion criteria for the study.

The purpose of the research proposal was therefore to establish how respite care addressed the needs of palliative care service users and carers. Its aim was to explicitly explore their perspectives and experience of respite care and as such, reflect more deeply on what on the one hand seemed to make respite care so apparently important to service users and carers but on the other create an uneasiness that manifested itself in the reservations – the 'buts' – that are expressed in feedback about respite care from service users and carers.

#### **1.4 Aims of the research**

I identified three aims of the research as follows:

1. To explore the perspectives and experience of palliative care service users and carers of respite care.
2. To establish how far respite care addresses the needs of palliative care service users and carers and whether either party benefit from it.

3. To capture the dynamics of the caring relationship and explore the impact of respite care on the continuity of that relationship.

It is important to note here that although the original aims of the research were not concerned with focussing on one particular type of caring relationship, the final sample was eventually made up of married couples or bereaved spouses who had cared for their partners within the marital relationship. Therefore, while the original aims of the research remained as stated above, the reader should be aware that the relationships explored are specific to palliative care service users and carers in spousal relationships. This development is discussed further in Chapter 3

With reference to the final aim, this was a reflection of how my research was going to be more than an evaluation of respite care. My feeling was that by exploring the experiences of service users and carers, it would explicitly break down the components of the process of the need for respite care and demonstrate how it affected the relationship between the carer and the cared for; the carer, the cared for and the hospice; the carer, the cared for and society. In my preliminary work on the study, I was struck by the ease in which our society referred to the importance of 'respite care' without setting it in any sort of context that acknowledged that there was a relationship at the heart of the work of caring for somebody – something that is acknowledged in the Australian literature (Herz et al, 2006). If we acknowledge this, how acceptable is it for a health care system to divide and separate people when they perhaps need each other most? (Clarke, 1995) My research was therefore set to explore the discourses that I felt were implicit in the rather trite concept of respite care which I felt may have its roots in the discursive practices of healthcare as identified by Gilman et al (2000).

## **1.5 The setting for the research**

The participants in the research were all service users and carers who were registered with The Oaks Hospice. The Oaks Hospice is a fictitious name for the setting in which I work and in which I carried out my research. I have used pseudonyms for the participants' names and the fictitious name of The Oaks Hospice throughout my thesis in order to protect the participants' anonymity (Royal College of Nursing, 2004) and to reduce the possibility of their identities and those of other settings referred to being revealed (Orb et al, 2000). For the purposes of ethical consistency, in addition to this strategy being used in the main body of the thesis, it is continued in the title page, references and appendices. I will explain and explore the importance of this and other ethical considerations in more depth in forthcoming chapters. The participants had all experienced at least one period of respite care at The Oaks Hospice and this hospice was the setting for the research. The Oaks Hospice is an independent voluntary organisation that was first registered as a charity in 1980. The roots of the hospice are embedded in what is recorded as a desire that sprang from the local community to create a place where "greater provision should be made for the incurably sick in a loving atmosphere" (Hall, 1996, pg 7). Beginning in 1983 with the provision of nurse led day care supported by volunteers at a local convent, the hospice moved to purpose built accommodation in 1991 and opened its doors to its first inpatients in 1992. It now provides specialist palliative care (SPC) including end of life care for adults over the age of 18 with any type of progressive life limiting illness. Situated in the north of England, the hospice serves a population of approximately 500,000 people over half of which suffer poorer health than the English average with high rates of deprivation and low rates of life expectancy. The hospice is typical of other UK hospices in that it is heavily reliant on its own fundraising to finance its

charitable activities and volunteers to support the delivery of these activities. The hospice has 20 inpatient beds, day care and outpatient clinics. It also provides rehabilitation services, complimentary therapies and a psychosocial and spiritual care team. Within the 20 SPC beds, there are 2 respite beds and respite care is also provided on a day care basis. The hospice also has an education department. The services The Oaks Hospice provides are in keeping with the range of services that hospices across the UK may provide as described by the umbrella organisation of hospices in the UK, Help the Hospices. They are:

- "Pain and symptom control
- Psychological and social support
- Palliative rehabilitation – helping patients stay independent
- Complementary therapies including massage and aromatherapy
- Spiritual care
- Practical and financial advice
- Support in bereavement" (<http://www.helpthehospices.org.uk/about-hospice-care/what-is-hospice-care/> Accessed 2 March, 2013)

These services are provided within a context of care which "aims to improve the lives of people who have a life-limiting or terminal illness, helping them to live well before they die". Within this, carers, family members and close friends are also supported both during a person's illness and during bereavement. Although as with all hospices, there are individual variations in the range of services it provides, The Oaks Hospice adheres to these core principles of hospice care and as such could be said to be typical of hospices in the UK today.

## **1.6 Deciding on the design of the research and the development of reflexivity.**

In the way that the discussion group at the hospice's Listening Day had been significant in my deciding on respite care as the research area for my study, deciding on the design of the study was influenced by an equally significant event that took place during the taught part of my doctoral journey. In the module on identifying and managing one's own learning, I set myself the aim of increasing my knowledge about the most appropriate methodologies to use in research with palliative care service users and carers. The interesting thing was that it was in learning about how people learn and how I would meet my own learning objectives that I was actually developing my research perspective and where I would sit in relation to my own research. This was a significant discovery for me because up until this time, I had perceived research methodologies as something 'cold' and detached from my view of the world and I can remember feeling daunted by the learning objective I had set myself. However, in learning about approaches to learning styles that emphasise the student's potential to change and the power of collaboration and interpretation, I gradually felt less detached from the subject I had thought of as 'cold' and on reflection, the seeds of the design for my own research were being sown. Becoming familiar with the work of Freire (1998), Race, (1994), Brufee (1999) and Gergen (1999) introduced me to the principles of learning through collaboration and dialogue as being fundamental to social constructionist theories. It was through this process that I realised that far from being detached from research methodologies that I had perceived as single truths set in stone by those who understood, they were open to interpretation with multiple meanings and in learning about them, I was developing my own understanding of my view of the world. Crucial to this learning was a conversation I had with a friend, a nurse by background, who had carried out palliative care

research herself for her PhD. This conversation was really significant for me as she helped me to understand that in choosing a methodology for my own research, there was not one right answer as the text books might have led me to believe and that it was about choosing a methodology that would provide a framework through which I could explore the complexities of the lives of the people participating in the research. And probably most importantly, she helped me to understand that the methodology a researcher chooses cannot be separated from them and that far from being detached from the methodology, I was actually part of it in the sense that it was about what I believed in and what was important to me.

This learning enhanced my understanding of research methodologies but it also developed my understanding of reflexivity in the sense of having an on-going relationship with the research where I would need to be prepared to continually adapt and change to the complexity of “the different truths and experiences of participants” in the research (Sargeant, 2004, pg 77). That my beliefs and experiences were crucial to this process was a significant milestone in my learning.

I also learned at this time that ethical issues in qualitative research are “inextricably tied to matters of methodology” (Seymour et al, 2005 pg 172) and that “the development of research designs for the examination of palliative care issues is particularly challenging” (Seymour and Ingleton, 2005, pg 139). In research related to palliative care, the ethical and methodological challenges of qualitative research are likely to be magnified because of the vulnerability of palliative care service users and carers and the potential for harm (Seymour et al, 2005). This therefore reinforced to me that my chosen methodology would need to provide a framework in which I could be particularly sensitive to the ethical issues of

research with palliative care service users and carers. Ethical considerations are discussed further in Chapter 4.

All of this learning helped me to develop a paradigm for my study which I felt was at one with my view of the world and which I also felt would promote the level of sensitivity needed for research with palliative care service users and carers. In brief, for the purposes of the introduction only, the research approach I decided on was qualitative. Based on all of my learning at this time, the methodology I felt was most appropriate for my study was interpretive and the method was to be constructivist Grounded Theory. Forthcoming chapters will provide in depth explanation of all of the issues related to the decision making around these choices and how they have added to the distinctiveness of the study.

### **1.7 Distinctiveness of the research and how it adds to the existing literature**

Because of the indications that over the coming years as an ageing population with multiple chronic illnesses increases, an increasing amount of support for carers of patients with palliative care needs will be needed (Wolkowski et al, 2010) my research question is as important now as it was at the beginning of my research journey. Learning more about respite care as experienced by palliative care service users and carers helps us to have a better understanding of whether respite care can be “a key factor” (Wolkowski et al, 2010, pg 388) in supporting carers in this context. However, more than remaining important, recent developments like the recommendations from The End of Life Care Strategy (2008b) which have blurred the boundaries between palliative and end of life care and driven directives to encourage more deaths at home, in my view, add substantially to the importance of my question and the significance of the findings. Primarily I hope that the study will engage the reader by creating a new

perspective or viewpoint on a familiar problem (Chenitz and Swanson, 1986) that although familiar is in practice poorly understood.

## **1.8 Structure of the thesis**

This section gives a brief overview of each chapter

- **Chapter 2: Review of the literature**

Beginning with a justification for the review of the literature in a Grounded Theory study, the chapter establishes that the literature review provides an orientation to the subject of study rather than a defining framework. It is divided into the initial literature review which I carried out at the beginning of the study and the later one which occurred as part of theoretical sampling. The chapter also shows how reading the literature was an ongoing process throughout the study.

- **Chapter 3: Philosophy, method, research design and process**

This chapter describes the conceptual framework of the study and its theoretical underpinnings. It explains how the approach used in the research is qualitative, the methodology interpretive and that the method used is Grounded Theory. Within this, there is discussion about reasons for these choices including the relationship between the philosophy underpinning the research and the method itself. The chapter describes the design of the research and within this, the impact of the researcher as practitioner on the research process is explored. The ethical approvals obtained for the research are described and the chapter goes on to explain the sampling strategy and the nature of the sample itself. This section also introduces the particular challenges of protecting anonymity when research is carried out within the researcher's own organisation and the strategies I employed to address those challenges. It then continues to describe the



process of data collection and the particular features of data collection in Grounded Theory including the constant comparative method, memo writing and theoretical sampling. The chapter concludes with a section on data management.

- **Chapter 4: Ethical considerations**

This chapter aims to provide the reader with an awareness of the ethical and methodological challenges that could be said to be specific to research with vulnerable people and most particularly, people with palliative care needs. Within the chapter, I describe the ethical context and framework for the research and the final section is devoted to the development of reflexivity in myself as researcher/practitioner. Within the chapter, I show how ethical considerations affected my study and how I addressed the challenges that arose.

- **Chapter 5: Analysing and interpreting the data**

I consider this chapter to be at the heart of the study as it is the place where the voices of the participants truly emerge. Through the use of Grounded Theory coding strategies, I am able to demonstrate how data was analysed and interpreted. In keeping with Grounded Theory, this includes data from other sources including literature, practice discussion and supervision. The chapter shows how categories are developed and how through the use of coding, memo writing and theoretical sampling, theoretical saturation is reached and integration of concepts achieved.

- **Chapter 6: Developing a theory: finding meaning and interpreting the data**

The findings from the study are presented in a way that is in keeping with the theoretical underpinnings of the research and as such they are

presented in a way that reflects a constructivist method within an interpretive approach. The chapter describes the theoretical concepts which emerged from the study and it is through these concepts that findings are interpreted and meanings found. A section which is entitled 'capturing the emerging theory' concludes the chapter and encourages the reader to join me in interpreting what we have learned together from the analysis in order to develop a shared understanding. This section introduces the following chapter in which the findings are explored further and the new knowledge that has emerged from the study is identified.

- **Chapter 7: Integration and Discussion**

This chapter will demonstrate how the study has added to what have been identified as gaps in the palliative care literature about respite care and the discussion is developed through the framework of the theoretical concepts that emerged from the study. Within this, the need for a new palliative care approach to respite care is proposed and ways of achieving this are explained. The chapter concludes with recommendations for further research.

- **Chapter 8: Conclusion: reflections on the doctoral journey**

The conclusion provides the reader with a summary of the research journey and a reflection on a constructivist Grounded Theory study and the researcher's own journey within the study.

- **References**

This section contains a detailed bibliography of references used in the study.

- **Appendices**

Appendices included are as follows:

Appendix 1: Wolkowski et al, (2010), "What does respite care mean for palliative care service users and carers? Messages from a conceptual mapping", *International Journal of Palliative Nursing*, 16 (8) pp. 388-392.

Appendix 2: Preliminary information on research proposal (handout).

Appendix 3: Information sheet for participants.

Appendix 4: Invitation letter for participants.

Appendix 5: Consent Form.

Appendix 6: Ethical approval letters/emails

Appendix 7: Extract of anonymised transcript

Appendix 8: Reframing respite care (example).

## Chapter 2 Review of the literature

### 2.1 Introduction

Having decided that Grounded Theory was the most appropriate method for me to use for my study, I needed to be able to establish my position on the issue of how the literature relevant to the research topic should be used (Bryant and Charmaz, 2007) as this is not straightforward in Grounded Theory. Grounded Theory emerged from the work of sociologists Barney G. Glaser and Anselm L. Strauss who first jointly described the method (Heath and Cowley, 2004) in the “The Discovery of Grounded Theory” (Glaser and Strauss, 1967). Whereas quantitative research demanded that time was spent reviewing the literature before the research began (Heath and Cowley, 2004), a defining component of Grounded Theory was “conducting the literature review *after* developing an independent analysis” in order to “avoid seeing the world through the lens of extant ideas” (Charmaz, 2006 pg 6). This approach sits well within the Grounded Theory method which emphasises discovery and developing new perspectives on familiar problems. It seems entirely in keeping with it that researchers should not be hindered by the preconceived ideas of the past. However, although this is not desirable, to have an awareness of the “current theoretical conversation” in one’s research area (Lempert, 2007, pg 254) could be seen as essential in terms of developing theoretical sensitivity and also providing a baseline from which to work if the expectation of the research is that the existing knowledge will be added to and a unique contribution made. The issue of the “disputed literature review” (Charmaz, 2006, pg 165) is debated (Bryant and Charmaz, 2007) but Heath and Cowley (2004) point out that Glaser and Strauss both acknowledge that “the researcher will not enter the field free from ideas” or as Heath and Cowley add themselves (2004) “completely free from the influence of past experience and

reading” (Heath and Cowley, 2004, pg 143). This was in keeping with my own position in that respite care for palliative care service users and carers was an area in which I had expertise and I was therefore already aware of literature relating to it. Therefore, using Grounded Theory strategies flexibly (Charmaz, 2006), I decided that the desirable balance was probably to be found between:

“reliance on the literature to provide the framework to start with, something that Glaser and Strauss particularly took issue with, and having a level of understanding to provide an orientation as Lempert advises.” (Bryant and Charmaz, 2007, pg 20).

Bryant and Charmaz (2007) refer to Lempert (2007) describing the preliminary literature review as orientation rather than “a defining framework” (Lempert, 2007, pg 350). Although I could not deny that my initial literature review had not influenced my research question, I felt on learning more about Grounded Theory, that while it meant that I was not strictly at one with the method as originally defined by Glaser and Strauss, the review did provide me with “an orientation” (Bryant and Charmaz, 2007) around the subject and a starting point from which to explore. I was therefore content to proceed in the knowledge that I would return to the literature review later in the research. By this stage I would be able to compare themes from my study with concepts in the literature and begin to place my study appropriately within the literature (Charmaz, 1990).

## **2.2 Initial review of the literature**

This was based on a literature search using the words respite care AND palliative care. I chose to set these limits on the review because as described above, the aim of the initial review was to provide me with an orientation to my subject rather than a defining framework. This and returning to the literature later in the research process is typical of a Grounded Theory approach (Charmaz, 2006, Holton, 2007,

Lempert, 2007) and demonstrates my understanding of the concerns regarding how Grounded Theory students and researchers should approach and use the existing literature relevant to their research topic (Bryant and Charmaz, 2007). The review demonstrated a limited evidence base for respite care for palliative care service users and carers. Using the Northumbria University Library search system, databases that produced results were CINAHL, ProQuest, ASSIA and Blackwell Synergy. I also used hand searching techniques. The three key papers which I identified in this initial review came from researchers based in Sheffield University which was at that time home to the Palliative and End of Life Care Research Group (Ingleton et al, 2003, Payne et al, 2004, Skilbeck et al, 2005). As the first of a trio of papers which focus on respite care for palliative care service users and carers, Ingleton et al (2003) start by setting out the concern that one of the most common reasons for unplanned admissions towards the end of life is because of the carers inability to continue providing care. They add that respite care has been offered as a strategy to overcome the challenges associated with caring for someone who has advanced disease and who may be in the terminal phase. In doing so, the authors indicate the potential importance of respite care in enabling patients and carers choice about their preferred place of care at the end of life.

By starting with a review and discussion of the literature on “respite in palliative care” (Ingleton et al, 2003, pg 567), Ingleton et al lay the foundations for the programme of research presented by the Sheffield group in the other two papers in this set (Payne et al, 2004, Skilbeck et al, 2005). The second one of these being a survey of the perspectives of specialist palliative care (SPC) providers in the UK of inpatient respite care (Payne et al, 2004) and third, an exploration of family carers’ experience of respite services in one hospice (SPC unit) (Skilbeck et al, 2005). The review and discussion of the literature carried out by Ingleton et al,

(2003) identified 260 papers of which only 28 related directly to adult respite care in SPCS. Out of these, they found “insufficient evidence to draw conclusions about the efficacy of offering respite care to support carers of patients with advanced disease” (Ingleton et al, 2003, pg 567). However, by drawing on the wider literature of carers of adults with chronic disease, they were able to consider the impact of respite services and offer suggestions for further research. Conclusions drawn include the following:

- That there is evidence of high levels of anxiety and emotional and physical exhaustion in carers of patients with chronic diseases.
- That there is a pre-eminence of the negative view of the ‘burden’ of caring and of the patient as a ‘burden’ (Ingleton et al, 2003, pg 568)
- That there is little evidence for the clinical effectiveness of inpatient care in respite.
- That there is a dearth of studies on satisfaction from the view point of family carers in their own right rather than as proxies for patients.
- That there is a problem in evaluating respite in palliative care because the definitional boundaries between ‘respite care’ and ‘symptom control’ are often blurred and therefore it is impossible to assess whether specific services have been effective (Ingleton et al, 2003, pg 571).
- That “a gap in the knowledge about the impact of respite on carers has been identified” and “that there is much that is not known about respite provision for carers” (Ingleton et al, 2003, pg 573).

In making recommendations for further research, the observation is made that researchers should make more effort to engage in meaningful dialogue with carers if planned interviews are to be more appropriate and sensitive. The following recommendations for research are made. To find out:

- The extent to which respite care functions to reduce physical and psychological morbidity.
- The extent to which respite care enhances wellbeing and perceived control.
- The extent to which respite care enhances choice which may include the decision to cease caring (Ingleton et al, 2003).

The emphasis on the gap in knowledge particularly around the effect of respite care on carers is to be found in an earlier UK systematic review (McNally et al, 1999) referred to by Ingleton et al (2003) and, I discovered later, often referred to in the more recent palliative family carer literature as highlighting the evidence of the lack of research in this area (Wolkowski et al, 2010). The aim of McNally et al's (1999) paper was to examine research on respite provision with a view to establishing what effect it had on carers. This paper, which found 29 studies on respite care, did not focus on palliative care specifically, but similar themes emerge to those found in the later Ingleton et al (2003) paper. These include:

- A lack of consensus about the benefits of respite care for carers. They report that 'evidence of the efficacy of respite to enhance well being among carers is far from overwhelming' (McNally et al, 1999 p13).
- That a more carer centred approach should be adopted to both the provision and evaluation of respite services which would address the experiences of both the care giver and care recipient during the respite period.

Ingleton et al, (2003) also suggest that there needs to be an increased understanding of the attitudes of professionals towards caregivers. The second of the Sheffield papers which reports on the results of a survey of inpatient respite care provision provided by SPCS and hospices in the UK (Payne et al, 2004) captures this concern and concludes that "carers' needs and wishes are not



prioritized” by such services (Payne et al, 2004, pg 692). In addition, in the survey which had a 69% response rate from hospices and SPCS showed that although there was an ambivalence towards providing respite care that seemed to be based on a lack of consensus on the purpose of respite admissions, there was a widely held view that respite care offered mutual benefits to patients and carers. A key recommendation is “that a consensus definition of respite should be developed and clear criteria agreed for the purpose of respite services” (Payne et al, 2004, pg 697).

The third paper on respite care from the Sheffield group which explores family carers’ experience of respite services in a local hospice focuses very much on what is considered to be a gap in the literature – the carer experience of respite care. Skilbeck et al (2005) introduce the paper by stating that:

“Despite recent studies, little is known about respite services for patients with life limiting illness, in particular how respite is experienced by the caregivers or to what extent respite services address their needs” (Skilbeck et al, 2005, pg 610).

Through mixed methods of data collection, the study explores the experiences of 25 family carers whose relative had been admitted to the local hospice for inpatient respite care. In spite of difficulties recruiting carers to the research – an issue which is discussed - the study found that the majority of carers valued the respite services offered by the hospice. However, the authors also concluded that many issues were raised that needed to be considered in supporting carers who were caring for relatives with life limiting illnesses which had uncertain trajectories. For example, was a hospice the right setting for respite care? Some carers spoke about the negative connotations associated with the hospice as being a place where people came to die. However, on the other hand, some carers spoke about the value of their relative being able to participate in rehabilitation activities and

complementary therapies at the hospice. Overall, the hospice was appreciated for the high quality of care it provided and there was disappointment expressed that the provision was being reduced as other services were often considered not satisfactory. Issues were also identified in relation to the carers experience of stress and respite care – the latter not always being the reliever of stress that it might be considered to be. In summary, while raising many questions about how carers are supported, the study “illuminated the experiences of a small number of carers” who had used respite care services (Skilbeck, 2005, pg 617).

Together, the three Sheffield papers highlight the lack of research in this area and through the studies that followed Ingleton et al’s review and discussion of the respite care literature (2003), Payne et al (2004) and Skilbeck et al (2005) go some way to address this. The discussion in each of the respective studies describes their limitations. Payne et al (2004) highlight that while the response rate (69%) to their descriptive survey on the perspectives of SPC providers of respite care in the UK almost reached what is generally regarded as the threshold value for achieving a representative sample (70%), the interpretation of the findings was limited by the cross-sectional nature of the survey. They recommend that longitudinal studies are needed to properly determine the reasons for changes in the pattern of service provision over time (Payne et al, 2004). They also concede that the respondents were predominantly nurses and that a more complex picture may have emerged by taking into account the views of other service providers and service users. This limitation was addressed in part through what was the concurrent study being carried out at that time (Skilbeck, 2005) exploring the perspectives of patients and carers of respite care at one hospice. However, in spite of these limitations, I believe Payne et al’s (2004) study has real strengths in that as the authors say themselves, it “provides evidence of inpatient respite

utilization that is useful to healthcare workers and policy makers” (Payne et al, 2004, pg. 696) at a time when evidence had previously been purely anecdotal. By focussing on “the nature, purpose, organisation, delivery and definitions of respite services” (Payne et al, 2004, pg. 693) for palliative care patients and carers, the authors were doing something that had not been done before at a time when establishing the nature and efficacy of respite care for this group of patients and carers was becoming increasingly important. While the authors acknowledge that a more complex picture may have emerged by taking into account the views of other providers and service users, by giving respondents the opportunity to give their perceptions of respite care in free text at the end of the structured questions, they capture the sort of contradictory views which indicate that the issue of respite care is unexpectedly complex and that it warrants further investigation. This of course is valuable in itself and it is this sense of respite care being complex and contradictory that the reader can take into the concurrent study (Skilbeck et al, 2005) as described above. This study used a combination of methods to explore family carers expectations and experiences of respite services provided by one hospice. They explain that less than one third of the carers invited to participate in the study agreed to take part, with the views of the remaining two-thirds remaining unknown and although the authors do not describe this as a limitation of the study, they say that “it must be noted” and that “results should be interpreted within this context” (Skilbeck et al, 2005, pg 615). I was very much aware of the difficulties of recruiting patients to palliative care research and the authors do talk about this specifically for them in terms of the limitations put on them by the local research ethics committee who required that the consent of the patient was required for the carer to take part (Skilbeck et al, 2005). They explain that needing the approval of the patient made it difficult for carers to be approached and in turn affected the

numbers of carers who participated. This may well be the case but I did wonder also whether, bearing in mind the vulnerability of this population, that a letter of invitation may not have been enough in itself to encourage a response from a population that the literature has already shown suffer from high levels of anxiety and emotional and physical exhaustion (Ingleton et al, 2003). This group may simply not have the time or energy to respond. However, 25 patients did respond and their experiences of respite care at the hospice are explored through a combination of qualitative and quantitative methods. These are semi-structured interviews before and after a period of respite care and the inclusion of The Relative Stress Scale Inventory (RSSI) at both of those points. There are advantages to using questionnaires like the RSSI for example, because they are structured, predetermined and cannot as a rule be varied. They are also considered to provide “a fair degree of reliability” (Parahoo, 2006, pg. 298) but there is no doubt for me that the most valuable insights in this study were gathered from the individual interviews. Without these the RSSI, particularly with the small number of respondents, would have been of limited value (Skilbeck et al, 2005). As it stands, the RSSI reinforced the hard physical and mental work of caring which as the authors explained, is consistent with the caring literature. What I found interesting was that the combination of methods used produced findings that could be said to be contradictory in that the findings from the interviews showed that the majority of carers in the study felt that their expectations of respite care for themselves had been achieved. However, in the RSSI, the results showed respite care to be of arguably negligible value:

“Four carers experienced a small positive change in scores following the respite stay, three experienced no change, and for five carers there was a negative change in scores following the respite stay.” (Skilbeck et al, 2005, pg. 613)

If the RSSI had been self administered, these contradictions may have been explained by what Parahoo (2006) describes as a major advantage of questionnaires, “the absence of interviewer effect” (Parahoo, 2006, pg 298). When questionnaires are completed independently, the suggestion is that the respondent is able to answer questions in a way they may not if being asked by an interviewer. For example, they may feel uncomfortable about speaking to an interviewer about a particular issue, but they may feel less inhibited about writing the response without the presence of an interviewer. However, in the Skilbeck et al (2005) study, the RSSI was administered by a member of the study team during interviews with the carers and so the absence of interviewer effect was not a factor. Therefore these contradictions reinforced to me that respite care was problematic and that there was still much to learn about respite care for palliative care service users and their carers.

The three Sheffield research programme papers together provided me with an excellent orientation to the subject of my study. At this time, I also identified a review of neurological patients attending a nearby hospice for respite care (Owen and Johnson, 2005). I found this paper while searching literature by hand in a journal which was not on an electronic database, The European Journal of Palliative Care. Reinforcing that research regarding respite care was very limited, the review established that ‘respite’ rarely turned out to be ‘respite’ as patients usually had “a vast array of problems” which required interventions. (Owen and Johnson, 2005 pg 196) They argue that maybe a more appropriate term for these planned breaks would be ‘regular inpatient assessment and symptom control’. This of course confirms the view of the Sheffield group that in respite care, the needs and wishes of carers are not prioritised and “the basic problem of definition”

with respite care (Owen and Johnson, 2005, pg 197) which they conclude is evident, added to my sense that there was an underlying confusion about the purpose of respite care which I felt may have been linked to the ambivalence expressed about it by some hospices as demonstrated by Payne et al (2004). Owen and Johnson (2005) go on to recommend further research on respite care which they suggest should include the views of patients themselves, in order to clarify the role hospices may have in determining what their role is in regard to its provision.

### **2.3 Reading the literature and returning to the review**

As forthcoming chapters demonstrate, one of the ways in which Grounded Theory is characterised is that data can come from many sources (Charmaz, 2006) including reading. “When someone stands in the library stacks” wrote Glaser and Strauss in 1967, “he is, metaphorically, surrounded by voices begging to be heard” (Glaser and Strauss, 1967, pg 163). In this way, reading and reviewing the literature was an ongoing process throughout the study, creating a theoretical interplay between the data from the participants and the data from other sources including reading, supervision, talking with colleagues etc. However, in terms of reviewing the literature about respite care and palliative care service users and carers, I did not return formally to this process until the theoretical sampling stage of the study. This was also a time when my supervisors and I decided to write a paper identifying the key messages from the literature on respite care in palliative care in order to bring my work into the public domain. This paper was therefore developed from “an accumulative review of the literature” over the previous three years (Wolkowski et al, 2010). It is attached as a publication (Wolkowski et al, 2010) (Appendix 1) and may be read in conjunction with this chapter. The key messages from the literature are presented in a conceptual map under the

headings of “the definition and purpose of respite care”, “the existing evidence base”, “the role of hospices and specialist palliative care services” and “models of care” (Wolkowski et al, 2010).

#### The wider context of family carer literature

My return to the literature saw a marked change in the context of references to respite care for palliative care service users and carers. In UK policy and guidance (National Institute of Clinical Excellence (NICE) 2004, Department of Health (DOH), 2005b, 2006, 2008a, 2008b), I found that respite care was frequently mentioned as a key factor in supporting carers so that they may carry on caring for longer and have an improved quality of life (Wolkowski et al, 2010), but studies specifically about respite care were still limited. There was an increase though in the amount of literature concerned with family carers and their role in supporting patients who are nearing the end of life. In 2009, the European Association for Palliative care published a “White Paper” on “Family Carers in Palliative Care” (EAPC, 2009). Written by Payne et al (EAPC, 2009) in acknowledging that “family carers are central to the provision of palliative care for patients” (EAPC, 2009, pg i), this paper provides a scoping of the literature concerning situations and issues faced by carers in palliative care settings across the world and its purpose was “to highlight the contribution of family carers to the care of patients in the palliative phase of illness” (EAPC, 2009, pg 1). A number of important points are made and had relevance to my study including the following:

- That there will be an increase in demand for palliative care while the overall population declines meaning that there will be fewer people available to provide paid and unpaid care.

- That there will be an increase in the amount of people coping with non-cancer chronic diseases that will mean prolonged and uncertain dying trajectories.
- That patient/carer relationships are complex with both parties having needs that may or may not be compatible.
- The importance of supportive social networks in increasing the possibility of patients dying at home.
- That there is little information about care giving for non cancer patients.
- That studies have shown that carers require a range of supports including respite care.
- That providing respite care is not straightforward and caregivers may not want to leave a patient who may die while they are away from them (Ingletton et al, 2003). The paper highlights a need for home respite care interventions.
- That few supportive interventions are supported by rigorous research.
- That respite care is provided in hospices, hospitals and in care homes and by sitting services and the main concerns are around being separated from the patient.

The paper identifies one example of a prospective study about respite care exploring experiences of family carers whose relative had been admitted for respite care in a UK hospice (Skilbeck et al, 2005). This is one of the few studies specifically about respite care for palliative care service users and carers and it formed part of my initial literature review. The view that there has been an encouraging increase in the emergence of carer intervention studies is acknowledged by Hudson and Payne (2009) in their work on family carers in palliative care, however in keeping with the EAPC report (2009), they add:



“...that there is still much to be done. The evidence base for some commonly used approaches to support family carers; for example, the use of family meetings and respite care, is lacking” (Hudson and Payne, 2009, pg 292)

In returning to the literature, I was reassured to find that there was still a relevant contribution to make to the evidence gap that I had initially identified in the literature in spite of the fact that there was without doubt an increased interest in the issues facing family carers in palliative care. There was also an increasing acknowledgement that family situations in the context of palliative care needs are complex (Harding and Higginson, 2001, Harding and Higginson, 2003, Samar and Kristjanson, 2005, Gomes and Higginson, 2006, Grande, 2009, Grande et al, 2009) and most recently, inextricably linked to the aspirations of The End of Life Care Strategy (2008b) ie being able to die at home.

#### Literature specifically concerning respite care

Literature that is specifically about respite care for palliative care service users and carers is limited (Hicks and Corcoran, 1993, Strang, 2002, Kristjanson et al, 2004, Payne et al 2004, Owen and Johnson, 2005, Skilbeck et al, 2005, McGrath et al 2006, van Excel, 2006, Satterley, 2007, Barrett et al 2009). The three papers specifically concerned with respite care for palliative care service users and carers that I had identified from The Sheffield Palliative and End of Life Research Group (Ingleton et al, 2003, Payne et al, 2004, Skilbeck et al, 2005) in my initial literature review remained the primary source of relevant information and observations relating to the subject of my study and together with the increased interest in family carer issues as described above, they also continued to provide inspiration for continuing to explore and develop categories in my study.

In addition to Owen and Johnson's (2005) review looking at reasons why patients attend St Catherine's Hospice in Scarborough for respite care, I was also able to allocate two other papers about hospice respite care. First, an earlier retrospective study of medical and nursing records of patients with MND at St Gemma's Hospice in Leeds (Hicks and Corcoran, 1993) and also an audit of respite provision at The Marie Curie Hospice in Newcastle upon Tyne (Satterley, 2007). These papers were interesting in that they all highlighted that admissions for respite care usually required interventions and Satterley (2007) established that the most common reason for respite care was pain and symptom control. Not surprisingly, Owen and Johnson (2005, pg 197) note that there appears to be a "basic problem of definition" in respite care and Hicks and Corcoran describe respite care as "a much misunderstood term" which can be taken to mean many things (1993, pg 148). What they all agree on is that although there is little research on respite care, their evidence is that much can be done for patients who are admitted to hospices for respite care. Hicks and Corcoran (1993) say that hospices should be encouraged to provide such services and Owen and Johnson (2005) add that there needs to be further clarity about the nature of respite care so that patients who have more complex needs have the opportunity to be admitted to the hospice rather than a nursing home which they feel would not be able to provide the level of care necessary for such patients. Satterley (2007) acknowledges this complexity and as a result of the audit, the term 'respite care' was dropped altogether at her hospice becoming "short planned admissions" (Satterley, 2007, pg 69) so that the patient would have the opportunity to benefit from interventions as well as the carer being able to have a rest.

It is interesting to note that the wider family carer literature puts the need for respite care within the context of support for the carer whereas the hospice papers

appeared to find that the need for respite care sits primarily with the patient's need for pain and symptom control. The potential different functions of respite care are outlined by participants in an Australian study of respite care (McGrath et al, 2006) for end of life care in the Indigenous people of the Northern Territory as follows:

- Primarily it gives carers "the opportunity to have a break from the demands of caring"
- To "keep the stress off the whole family system"
- An opportunity to "prepare for the patients care in the community"
- "An opportunity to improve the patient's physical condition" (McGrath et al, 2006, pg 152)

Although writing for a specific population with specific needs ie massive distances between home and services, McGrath et al (2006) have no reservations about stating the importance of respite care. They state that "respite care is now considered the cornerstone of care for many patient populations" (McGrath et al, 2006, pg 147) and they add that although few in number, where evaluations have been done, there is evidence of high levels of satisfaction.

Two other Australian studies focus on home respite care. Barrett et al (2009) describe respite care as "a key need" but with little evidence to support it. However, their evaluation of a qualified nurse home care respite service showed that such a service could reduce hospitalisation of patients and improve acceptance among carers. In their development and evaluation of a community night respite palliative care service for patients and family carers, Krstjanson et al (2004) found equally positive outcomes. Both of these studies showed that the nurse is highly valued in such interventions.

In Canada, Strang et al (2002) carried out a study to explore the experience of respite during home based family care giving for persons with advanced cancer.

This interpretive study showed there are many meanings of respite to family carers in this situation and interestingly, for some:

“respite was an opportunity to be with the dying member as much as possible, to enjoy activities together, and to achieve a normal pattern of life.” (Strang et al, 2002, pg 102)

Here, far from being about separation, respite care is about being given the opportunity to be together. One of the characteristics which marked this study out from others was that it was very specifically about caring for someone who was imminently dying which may not always be the case with palliative care service users and carers who we have already acknowledged may have a longer, more uncertain trajectory. The needs of the informal caregivers in the following Dutch study by van Excel et al (2006) may well have different needs. Although this questionnaire based study emerged in my literature search for palliative care respite care, the care recipients suffered from a number of different disorders including stroke, dementia and psychological problems. It should therefore be said that while my review of the literature has endeavoured to capture all the respite care literature that relates to palliative care service users and their carers, it is likely that there may be others that while not specifically about service users and carers with palliative care needs, may be just as relevant. In order to ensure the manageability of the literature for the purposes of this study, I have concentrated on identifying studies where palliative care is the primary concern. However, as the coming chapters identify, there is now much that is blurred about the definition of palliative care (Payne and Seymour, 2008) which together with the problems of definition in respite care confirm Ingleton et al's views that studying the effects of it is problematic (Ingleton et al, 2003). This may well go at least some way to explaining why there is a lack of research on respite care in relation to palliative and end of life care needs (Wolkowski et al, 2010).

### Literature relating to respite care

As Wolkowski et al, (2010) show, respite care is frequently mentioned in the family carer literature in palliative care (Harding and Higginson, 2001, 2003, Payne, 2007, EAPC, 2009, Grande et al, 2009, Kellahear, 2009, Hudson and Payne, 2009) and within this, the lack of evidence supporting the efficacy of respite care for palliative care service users and carers and the issues around needs and acceptance are reinforced. As the researcher exploring the experiences and perspectives of respite care with palliative care service users and carers, all of the concerns raised in the literature as I returned to it in my study, encouraged me to continue to develop categories to shed further light on the much spoken of and yet poorly understood concept of respite care.

## **Chapter 3 Philosophy, method, research design and process**

### **3.1 The conceptual framework**

The underpinning concepts that are embedded in my approach to the research include learning from the experiences of service users and carers, the principles of critical practice i.e. respecting others as equals and having an 'open' and 'not knowing' approach (Brecht, 2000), and learning through relational endeavour i.e. constructing meaning through dialogue (Gergen, 1999). These concepts are in keeping with a Grounded Theory approach and underpin the development of theories as the research is done. The theoretical underpinnings of my research have in turn underpinned my practice vision at the hospice where I work as described in Chapter 1. Overlaying the theoretical underpinnings of the research there is an identification and analysis of the conceptual issues related to respite care such as formal and informal care and support and most specifically hospice care. Inherent in this study is the need to analyse the discourses implicit in the term respite care. From the literature, themes emerge such as a lack of clarity about the purpose of respite care, a pre-eminence of the negative view of caring as a burden, high levels of anxiety, physical and emotional exhaustion noted in carers and there is ambivalence towards respite care from both service users and carers as well as staff who are providing respite care.

### **3.2 The theoretical underpinnings**

My research question brings together several aspects of my learning so far. Together they form the theoretical underpinnings of the 'perspective' (Punch, 2000) which informs the research. In this case, 'perspective' is another way of saying the paradigm or the researcher's way of looking at the world. For example, a researcher may hold a positivist perspective. This would lead us to think that

his/her research would be based in empirical research traditions of the traditional sciences concerned with precise movement, replicability, prediction and control (Parahoo, 1997). It is likely that it would underpin a quantitative approach. Such approaches are largely based on the assumption that there is a single reality which can be uncovered or revealed by careful measurement, even with human behaviour (Robinson, 2003). Therefore, being aware of the researcher's 'perspective' gives us an indication of their view of the world, where they sit in relation to their research and what they expect to get from it. Similarly, but differently, the perspective that informs my research has been put forward as an alternative to positivism. Interpretism is the belief that the social world is actively constructed by human beings and that we are continuously involved in making sense of, or interpreting our social environments (Parahoo, 1997). This perspective counters the principle that there is an objective truth where human beings are potentially treated as objects in order to uncover that truth. An interpretive perspective recognises the possibility of multiple and complex truths. Whereas a positivist perspective could be said to deny humanness and thus deny the voices of those involved from being heard (Sargeant, 2004), an interpretive perspective would inform research that confirms humanness and actively seeks the voice of the participants.

Interpretism is the 'perspective' that underpins my research and the principles of critical practice and practice development that are pulled together within it. The following quotation from Steedman (1991) sums up my view of the world.

"It is worth noting here that, despite the intoxicating attraction of scientific positivism as the best or finest sort of knowledge, most of what we know is not, and never was, of this sort. Most of what we know, most of the knowing we do, is concerned with trying to make

sense of what it is to be human and to be situated as we are".(Steedman, 1991,pg.58)

So the aim of my research is not for me as the 'principal investigator' to establish some grand truth about the value of respite care for service users with palliative care needs; it is about making sense of their perspectives on and experience of respite care together as human beings. This view of the world is reflected in aspects of critical practice and practice development as follows:

- learning from the experiences of service users and carers
- embracing the principles of critical practice
- learning through 'relational endeavour'

#### Learning from the experiences of service users and carers

Developing a listening culture in which service users and carers are properly involved in the evaluation and development of services in the hospice which I manage has been my practice vision as I developed my research question. I believe that establishing this culture has been essential in ensuring that a structure was in place that would be receptive to my research question. This process has involved setting the vision in a practice context which has its roots in the history of the hospice and palliative care movement, (Saunders, 1988 and 1991/2, Saunders, 2003, Small, 2003), in current palliative care literature (NCHSPC, 2000, Small and Rhodes, 2000, Oliviere, 2001, Monroe and Oliviere, 2003, NCPC, 2004) and national guidelines (DOH, 1997, DOH, 2004, NICE, 2004).



Palliative care literature is passionate about the reasons why service users should be involved. A palliative care service user writes about how much being involved in “the management, organisation, planning and development of palliative care services” meant to her. “User involvement for me” she explains “is translating users experience into better services” (Broughton, 2003, pg 198). And in the same book, Professor Alwyn Lishman speaks as a carer about service user involvement:

“Perhaps no other element, on its own, can ensure so firmly that services develop in a truly person centred fashion” (Lishman, 2003, pg 195).

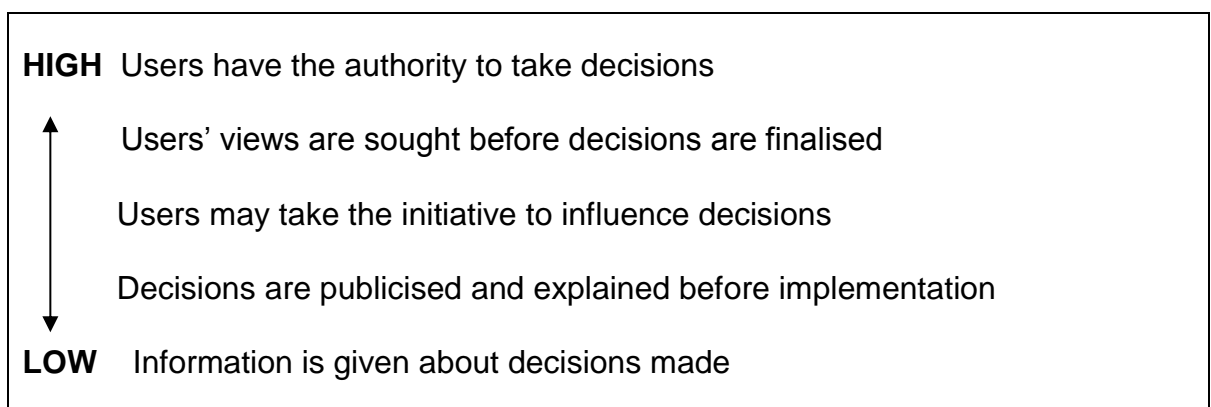
These were the voices that were inspirational to me as I developed my practice vision at the hospice but at the same time, user involvement was “firmly on the national and international agenda” (Small and Rhodes, 2000, pg 18) as the UK government at the time pledged their commitment to improving local services through including users and carers in developing those services (Small and Rhodes, 2000). In the background to their scoping study on user involvement in palliative care, Payne et al, (2005) describe how seeking the views of patients or trying to involve them in developing services as a relatively new experience for healthcare providers at this time and that development of user involvement in health care could be characterised in three periods of NHS development as follows:

“1948-1989 **Hierarchical structure** based on geographical regions with top down directives during which period citizens could vote for politicians who decided policy but generally British health service planning and provision was paternalistic and centrally directed.

1989-1997 **Market economy** model in which patients were positioned as consumers who could make choices but in reality choice of health care was limited by availability and decisions were made predominantly via GP fundholders.

1997- present [2005] '**User led' health care system** was the rhetoric of the 'New' Labour government in which patients and the public were positioned as the 'active citizen'. There are now formal requirements to consult service users at all levels of NHS activity." (Payne et al, 2005, pp.1-2).

Small and Rhodes (2000) explain how the term 'user involvement' is seen as a loose, umbrella term for any area where consumers are brought into the decision making process at any level. They cite Hoyes et al's (1993) 'ladder of empowerment' (see below) (Small and Rhodes, 2000 pg 19) to demonstrate that there are different levels of involvement that demonstrate different levels of empowerment:



(Hoyes et al, 1993 cited in Small and Rhodes, 2000, pg 19)

The 'ladder of empowerment' or "Dimensions of Involvement" as it is referred to in Payne et al, (2005) shows that "there are many levels to user involvement from tokenism and potential manipulation to empowerment and user-led services" (Payne et al, 2005, pg 3). This highlights how claiming to 'involve' service users may not necessarily be the marker of good practice that it suggests and how there is a need to be able to be clear about what is meant by service user involvement in the context in which it is being used. Within the context of my practice vision and in turn, a theoretical underpinning of my research, I feel that the definition of user

involvement as provided by Payne et al (2005) provides clarity and carries the potential for service users to be empowered:

**“User involvement** is taken to mean the way people, who use public services, are involved in making suggestions and taking decisions about how different services are run and developed. User involvement is about how service users are involved in shaping or building the future of public services” (Payne et al, 2005, pg 1)

In recognising that empowering service users and carers was a challenge to the status quo of the hospice establishment and that its success required a change in practice, I was able to utilise a case study approach to help me understand the dynamics of empowering service users and carers through a process of self-examination and examination of the processes involved in the development of service user involvement. And so I was able to see that empowerment of service users relies upon empowerment of staff and that the principle of staff learning *from* the patient rather than *about* the patient (Rolfe, 1996) is an empowering one for all concerned.

### Embracing the principles of critical practice

In working toward my research question and reflecting on my practice vision of developing a listening culture where service users and carers would feel able to contribute to the development of services, I was able to compare this process to the development of a culture of critical practice (Brechin, 2000). Brechin describes how, in a world where valued expertise is considered to be held by those who have the evidence based knowledge i.e., health and social care professionals, these ‘inequities’ of knowledge can create an ‘unequalness’ that devalues the contribution a service user or carer may make to service development or even decisions about their own care. It reinforces the positivist idea of the health and

social care professional being the expert and holder of the truth as it were. In a modern healthcare environment which welcomes the increasingly proactive role of service users, this unequalness has no place. In order to meet the demands of this new environment, a culture of critical practice needs to be developed; the two guiding principles of which are 'respecting others as equals' and having an 'open' and 'not knowing' approach (Breachin, 2000). These principles reinforce the idea that practitioners do not occupy a vantage point from which they make correct decisions. They offer the potential to break down barriers between service users and practitioners and promote the principle that both sides of the relationship can have something to offer. This is not about professionals giving up their knowledge but giving up the control that went with it to be able to operate alongside people in equitable relationships. Thus, the professional has a more uncertain, less knowing position as reflected in recent government guidelines on creating a patient led NHS:

“These are complex changes in a complex system. Moving from a centrally directed system to a patient led system inevitably increases uncertainty” (DOH, 2005, (a) pg. 4)

This uncertain, less knowing and more equal approach is essential to the development of a culture of critical practice and service user involvement. It also underpins where I sit in relation to my research and how I envisaged the relationship between myself as the researcher and service users and carers as the participants in the research.

### Learning through relational endeavour

As with service user involvement and the development of a culture of critical practice, I decided my approach should be based on listening to the voice of service users and carers and working with them as equals in an 'open' and 'not knowing' way. In my work on identifying and managing my own learning, I was particularly drawn to the concept of learning as being a 'human' process (Race, 1994) the outcome of which relies to a great extent on the human desire to 'want' to learn. By reinforcing the humanness of the process, it becomes accessible to all. The roots of Race's argument are in Paulo Freire's work (1998) who championed the belief that everyone is capable of "looking critically at the world in a dialogical encounter with others" (Shaul, 1998 p.14). In Freire's context, the educational experience is characterized by learning from each other rather than a passive process of receiving knowledge from an all-knowing teacher. Brufee (1999) develops this principle through explaining how we can achieve liberation (Freire, 1998) or as he puts it "re-acculturation" through "working together". In other words "collaborative working". Following on from this, I began to see how the principles of learning through collaboration and dialogue were fundamental to social constructionist theories which challenge traditional objectivist and rationalist views of inquiry (Steier, 1991). Gergen (1999) sees learning as a "relational endeavour" where meaning is constructed through dialogue rather than some pre-ordained individual style. And so the principle of my research being collaborative is embedded in this learning. I feel this prepared me for the reflexive nature of my research and the need to adapt and change to the complexity of "the different truths and experiences of the participants" within it (Sargeant, 2004).

### **3.3 The research method**

As the aim of the study was to explore the views of service users and carers, the approach is qualitative. This approach is described by one commentator as being “undoubtedly the best research method for researching many aspects of palliative care” (Wilkie, 2001, pg73). Such studies are based on an empathic relationship with the person and aim to document the person’s experience from their perspective. The methodology for the study is interpretive, the aim being to discover and promote understanding (Smith, 1997). Parahoo (2006) explains that interpretation is central to the exploration and understanding of social phenomena which defines qualitative research. However, qualitative research in itself is an umbrella term for a number of diverse approaches (Parahoo, 2006) that use a variety of methods to fulfil these aims and which also have a considerable amount in common (Carr, 1999). As such, I needed to choose a method which was in keeping with my view of the world and the theoretical underpinnings of my research at the same time as being a method which would provide the best vehicle for answering my research question and fulfilling its aims. The method I chose was Grounded Theory. Grounded Theory is a research method developed from the implications of the symbolic interactionist view of human behaviour; a principle of which requires us to understand the world from the participants’ perspective (Chenitz and Swanson, 1986). Formulated initially by Glaser and Strauss (1967) Grounded Theory is a general methodology for developing theory that is grounded in data systematically gathered and analysed (Strauss and Corbin, 1994). It should be acknowledged here that there are debates within the Grounded Theory approach that have their roots in the diverging paths taken by Glaser and Strauss soon after the publication of their seminal text “Discovery of Grounded Theory” (1967). While what has come to be known as Glaserian Grounded Theory is

characterised by an “unswerving faith in the notion of a truth waiting to be uncovered” (Mills et al, 2007), Strauss’ central concern moved away from that principle to the view that there is no one truth and that action should be at the centre of analysis (Mills et al, 2007). The symbolic interactionist view of human behaviour underpins Strauss’ paradigm which has led to further developments within the Grounded Theory method as demonstrated in the work of Charmaz (2006). Charmaz encourages us to use Grounded Theory strategies flexibly with the emphasis being on the researcher as participant in the research and an “*interpretive* portrayal of the studied world, not an exact picture of it” (Charmaz, 2006, pg 10). The approach is constructivist rather than objectivist (Charmaz 2000) in that it “necessitates a relationship with respondents in which they can cast their stories in their terms. It means listening to their stories with openness to feeling and experience.” (Charmaz, 2000 pg 525). In keeping with this, the researcher’s questions should aim to get at meaning rather than truth. This approach is in keeping with the theoretical underpinnings of my research as described earlier.

In choosing Grounded Theory, I did consider other qualitative research methods which may have been appropriate, the most notable of these being phenomenology. At one point, I felt that phenomenology may have been the most fitting method to use as its focus on the individual’s interpretation of their experiences and the ways in which they express them (Parahoo, 2006) was in keeping with the aims of my research and its theoretical underpinnings. Indeed, as Carr points out, “the distinction between a study guided by phenomenology rather than symbolic interactionism can at times appear tenuous” (Carr, 1999, pg. 81). Like Clare (2003), in her study using Interpretative Phenomenological Analysis, I too was interested in what the participants in my research believed and thought

about the topic in question. Interpretative Phenomenological Analysis, she goes on to explain:

“is phenomenological in that it aims to explore the participant’s view of the topic being investigated, and interpretative in that it acknowledges that the participant’s perceptions are elicited through a dynamic, interactive process in which the researcher’s own beliefs and understandings also play a part as the researcher engages in a process of interpretative activity in order to make sense of the participant’s subjective world” (Clare, 2003, pg. 1019).

However, although there are clearly similarities between a phenomenological and symbolic interactionist/Grounded Theory approach, it seems to me that a fundamental difference is that in the latter, it is the *experience* of the topic in question and the *processes* involved in that experience which set it apart from phenomenology and other qualitative approaches. In Grounded Theory, the study of action (Charmaz, 2006) or the “interaction of the parties involved” (Carr, 1999, pg.81) are central, rather than as in phenomenology, a description of the *essence* of the experience (Morse and Field, 1996) for that individual. In turn, as my understanding of Grounded Theory grew, my inclination to choose this method to guide my research increased and incrementally, I found more and more reasons why I should choose Grounded Theory above phenomenology.

Critically, as an intention of the research was to develop a theory, Grounded Theory was an appropriate method to use. This again is particular to Grounded Theory and moreover, in clarifying the differences between ethnography, discourse analysis, phenomenology and Grounded Theory which she feels all come under the umbrella of interpretative qualitative research, Parahoo (2006) points to the development of theory through induction as the specific focus of Grounded Theory which is not shared by any of the other methods. I also felt it was appropriate for a number of other reasons including where there is little known about the area of



study (Birks and Mills, 2011). In their research challenging the philosophy of partnerships with parents in children's wards, Coyne and Cowley (2007) use Grounded Theory because they say that in spite of the fact that there is much anecdotal literature and studies on parent participation, it remained in their view, a problematic issue that was poorly understood. They go on to explain that in such familiar situations, Grounded Theory can provide a "fresh perspective" which reminded me very much of the subject of my study and what I hoped to achieve. In addition, I discovered that Grounded Theory is a particularly popular choice with nurse researchers because it seeks to discover issues of importance in participants' lives (Mills et al, 2007) and it also seeks to affect practice (Strauss and Corbin, 1994).

The fact that the theory aims to have "at least some practical applications" (Strauss and Corbin, 1994, pg 281) sat comfortably with me as a nurse researcher for a number of reasons. Apart from any other considerations, I was concerned to be sensitive to the fact that service users and carers may face a sense of lack of time – indeed this may be their reality and that research participation may be stealing away precious time that participants may wish to spend in other ways (Addington-Hall, 2002, Seymour et al, 2005). As it has been shown that some patients with palliative care needs said that "when they had little time left, it was important that they could use that time to do something of enduring value" (Terry et al, 2006, pg 408), I found it reassuring to know that the theory my research aimed to generate may have the potential to inform subsequent service development (Clarke, 1995). As Clarke goes on to say, "it is also a timely reminder of the futility of gaining knowledge which is irrelevant to the participants and which is never applied to practice" (Clarke, 1995 pg 57).

The principle of my research having a practical application was not only important to me but a core requirement of a professional doctorate.

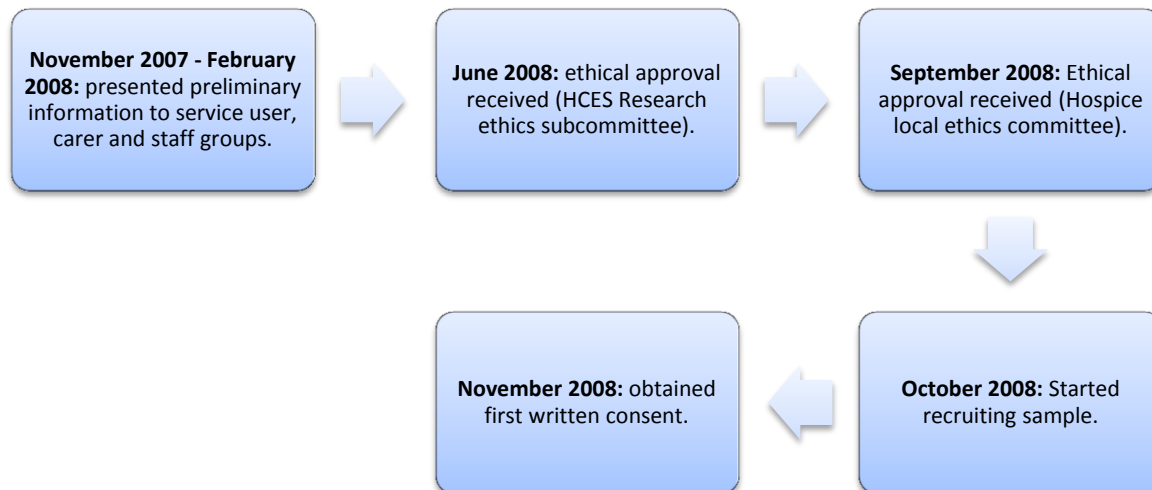
“ The legitimacy of professional knowledge and practice are implied within a professional doctorate. The student is required to engage with knowledge and expertise derived from the study of the professional context, using this knowledge to enhance practice” (Lee, 2009, pg. 95)

As such, maximising the potential for this became a key aim of the study and Grounded Theory became my preferred method.

### 3.4 The research design

The following route map (Fig 3.1) gives an indication of a timeline for the research preparation which is expanded on below.

Fig.3.1 Research design timeline



It is in keeping with a Grounded Theory approach that my perspective in the research and my practice vision is that I would want to involve service users, carers and staff in the groundwork of my study. As well as encouraging interest in the study and emphasising the fact that I wished to learn from service users and

carers, it was important that staff were on board with the research. Close collaboration with the healthcare team is an essential element in achieving the aims and objectives of any research study (Seymour et al, 2005) but gaining the approval and cooperation of peers in the research process of a professional doctorate could be said to be crucial in “using leadership to investigate practice in the professional context” (Lee, 2009). As such, I presented and discussed the aims and objectives of the research with the hospice’s service user forum, our carers support group, operational staff meetings, clinical governance meeting and executive management team meeting. I also provided individuals in the groups with hand outs (see Appendix 2 handout) with some preliminary information about my proposed study. I found these experiences quite anxiety provoking in the sense that I was ‘going public’ for the first time with my proposal. I felt a sense of trepidation that was similar to when I went on to interview my first participant. By this stage, my clinical colleagues (multi-disciplinary team members) and service user involvement coordinator were familiar with my ideas. We had all shared views on the provision of respite care at the hospice and they all took a keen interest in my proposal and how they could help. Some colleagues told me about service users and carers who they thought might be interested in taking part in the study and asked me if it was ok to approach people. Involving professional colleagues in helping to identify and recruit participants to the research process, “with due consideration and understanding of the ethical issues of informed consent” (Lee, 2009, pg 127) is acceptable in the context of the professional doctorate. I confirmed that this was acceptable in terms of my sampling strategy. By far the most vocal response I received in a meeting was from members of the hospice’s service user forum. I wrote in my diary straight afterwards:

“Really difficult but good! Quick points – my role – will it get in the way? What is my role at the hospice? Who pays me? What will happen to the results?”

I believe I was able to answer these queries and it felt positive to be able to say that the questions they had asked would help me in devising the content of the proposal's participant information sheet. Although a little shell shocked, I remember feeling pleased that I had been challenged in this way by service users who traditionally have been perceived as a group of patients who feel they can only be grateful for the services they receive (Hodgson, 2007). I also presented my proposal at the hospice's carer support group. The carers at the meeting had not experienced respite care and I got the impression that it was not something they had thought about at this time. Although I didn't receive any responses, members of the group were keen to take away my hand out with the message that they could contact me should they have any queries or ideas.

### Ethical approval

Ethical approval processes and requirements have changed recently and it is important that I locate the governance arrangements which were active at the time I undertook my research. As the reader will see from the research design timeline, ethical approval was received from Northumbria University's HCES Research ethics subcommittee in June 2008 and ethical approval for my study to be carried out at the hospice was received in September 2008 (see Appendix 6). At this time, unlike research carried out in an NHS setting, it was not necessary for research carried out in a non NHS setting such as an independent voluntary hospice to undergo NHS scrutiny (see Appendix 6). However, the research proposal, information sheet, invitation letter and consent form were all submitted to

the respective ethics committees of the University and Hospice and written favourable opinion was received (see Appendix 6). Since that time, governance arrangements have changed regarding research to be carried out in non NHS settings as defined in “Governance arrangements for research ethics committees. A harmonised edition” (Department of Health, 2011). As such, if the application to carry out research at the hospice (a non NHS setting) were being made today, then an application to The NHS Research Ethics Committee would be mandatory. Such an application would be made by completing The Integrated Research Application Form (IRAS) which ensures that appropriate arrangements are in place for the research to be carried out in “a non-NHS site”. This includes, for example, having the details of the person at that site with overall responsibility for the management and monitoring of the research. This and associated information can be found at [www.nres.nhs.uk](http://www.nres.nhs.uk) Such developments can only be welcome in ensuring that research with service users, wherever it is carried out, is subject to the same consistent level of rigorous scrutiny:

“This means the research must conform to recognised ethical standards, which include respecting the dignity, rights, safety and well- being of the people who take part. ...Researchers must satisfy a research ethics committee that the research they propose will be ethical and worthwhile.” (Department of Health, 2011)

### Impact of being a practitioner on the research process

This section highlights the consequence for the professional doctorate researcher on the research process. The research process I am describing is not one that would be likely to be familiar to a purely academic researcher. My research took place in the setting in which I work, with colleagues that I knew well within structures and arrangements that I was responsible for. This is in keeping with the

expectation of a professional doctorate where the central focus lies in the context of the student's professional practice rather than in the culture of academia where the domain of the research topic is likely to be within the discipline of the student's field of study (Yam, 2005). It is this difference in focus in the professional doctorate which has an impact on the research design and process. This in turn can be traced back to the development of practitioner research in which the notion of *improving practice* is acknowledged as being "the most important distinguishing characteristic" (Reed and Proctor, 1995, pg.12) of this type of research as opposed to traditional academic research. In describing the relationship between the researcher and the research subjects Reed and Proctor (1995) describe the practitioner researcher as "an insider" as they are undertaking research within their own setting. This is set against the more traditional view of the researcher who undertakes research into practice with no professional experience and who could therefore be described as "an outsider" or "visitor" to the research setting (Reed and Proctor, 1995, pg 10). The research design and process which I have described in my own research is therefore typical of that of the research practitioner as described by Reed and Proctor (1995). Within the framework of practitioner research, issues concerning choice of research setting and negotiation of role differ from that of "the outsider" researcher. In her ethnographic study of care within a specialist palliative care service in England, Sargeant (2004) describes how she chose and negotiated access to the research site. Very much "an outsider" in this sense, Sargeant's experience of weighing up the pros and cons of who she should approach and how is very different to my own experience of carrying out research in my own practice setting. Reed and Proctor (1995) explain that the insider practitioner researcher may occupy a number of different roles simultaneously within the research environment which can be extremely

complicated. Although the practitioner research they describe is primarily where colleagues are researching colleagues, some of the challenges they describe are reflective of my own experiences as a professional doctorate student carrying out research in my own practice setting with patients and carers who were receiving a service in that setting. It could be said that there are some advantages to this. I had “insider” knowledge of the organisation and its structures and arrangements. At a practical level, I did not have to concern myself with whether the site was in commuting distance for example and how much travel costs were likely to be (Sargeant, 2004). However, this familiarity with the research site and one’s ongoing relationship with it after the research has finished as a practitioner and as in my case, a manager, brings its own particular challenges. Reed and Proctor (1995) describe how difficult it is for example for the practitioner researcher to step in and out of role. More recently, Costly and Gibb (2006) further acknowledge this complexity by arguing that work-based practitioner research requires a different set of ethical considerations to that of research where the researcher is able to research and then leave the context of their research space. They recommend that within the context of practitioner research, additional ethical safeguards are required and that ‘an ethics of care’ should prevail in order to safeguard “personal and moral relations to others within that setting” (Costly and Gibb, 2006, pg 89). A recognition of these and other complex methodological issues related to the challenges of carrying out practitioner research were fundamental to my research design, process and ethical considerations and are explored further within this and forthcoming chapters.

### **3.5 Sampling strategy**

#### Sample size

The nature of the participant sampling was purposeful in that I selected the initial sample on the basis of which persons would provide the greatest opportunity to gather the most relevant data about the phenomenon under investigation (Strauss and Corbin, 1990). In this case, respite care. In my proposal, I stated that the aim of the initial sampling was to recruit 10 English speaking service users who had experienced at least one period of respite care either at the hospice or in another setting. They would in turn be asked to nominate their carer (over the age of 18) who could be interviewed. On reflection, I felt that deciding on a specific number was at odds with a qualitative design where size of sample is not the main concern. Qualitative data is often obtained from a relatively small number of sources (Birks and Mills, 2011) and the main feature is that it should be detailed, rich and complex (Punch, 1998) rather than extensive in size. However, some palliative care research has been criticised in the past for being too small in scale to draw generalisations from (Seymour et al, 2003). It may be though that these studies have been underdeveloped theoretically as in qualitative studies, generalisability lies in the applicability of theoretical ideas to other situations and settings. Thus findings or theoretical ideas emerging from one setting can be transferred to similar situations or participants (Holloway and Fulbrook, 2001). Guba and Lincoln (1989) use the term 'transferability'. Added to this, in a Grounded Theory study, while it is important to gather sufficient data to fit the researcher's task (Charmaz, 2006) there is technically no limit either way to how many participants might be needed as part of the theoretical sampling process in order to achieve theoretical saturation. This is controlled by the emerging theory (Glaser and Strauss, 1967) rather than a pre conceived theoretical framework. So



consequently, the number '10' was put aside in favour of recruiting an initial sample that I believed would best help me answer my research question.

### Recruiting the sample

Punch (1998) points out that there are no simple summaries of strategies for sampling in qualitative research because of the variety of research approaches, purposes and settings. However, he adds that there is a clear principle involved which concerns the overall validity of the research design and which stresses that the sample must fit in with other components of the study including the research question itself, i.e. learning from service users and carers, having an 'open' and 'not knowing' approach (Breachin, 2000) and learning through relational endeavour. I therefore adopted a combination of approaches in recruiting my initial sample. This involved consulting with service users, carers and staff as described above and from there, selecting participants who were most likely to fulfil the criteria. Basic inclusion criteria was that the service users and carers would be English speaking, that they had had at least one period of respite care at the hospice or another care setting, and that both service user and carer had an awareness of the prognosis. (Seymour et al, 2005). Exclusion criteria included communication difficulties or recent traumatic events. However, I soon found that I needed to be flexible regarding exclusion criteria as many palliative care service users and carers may fall into this category and two of my potential participants had communication difficulties. Seymour et al (2005) stress that in palliative care research, it is very important to hear the voice of those who are most likely to be the most muted, and of maximising participation particularly with people who may be disadvantaged by their illness and aspects of it such as difficulties with sight and speech. It was therefore up to me to be creative and do as much as possible

to enable these service users to participate. Also, two of the carers who were interested in participating were bereaved while I was in the process of recruiting my sample. Both women, and their husbands who they cared for, had been interested in participating in the research from an initial conversation, but sadly both men had died before I was able to meet with them to talk about the study in more depth. Sadly, this sort of problem is not uncommon in palliative care research (Karim, 2000). Both women were still keen to participate in the research and after discussion with my supervisors, we agreed that as they both felt very strongly that they had something important to contribute to the research, then it would not be ethical to exclude them at this stage. In the end, all of these people became participants in the study. This situation highlights the complexity and ethical challenges of operationalizing this methodology as discussed in the previous chapter.

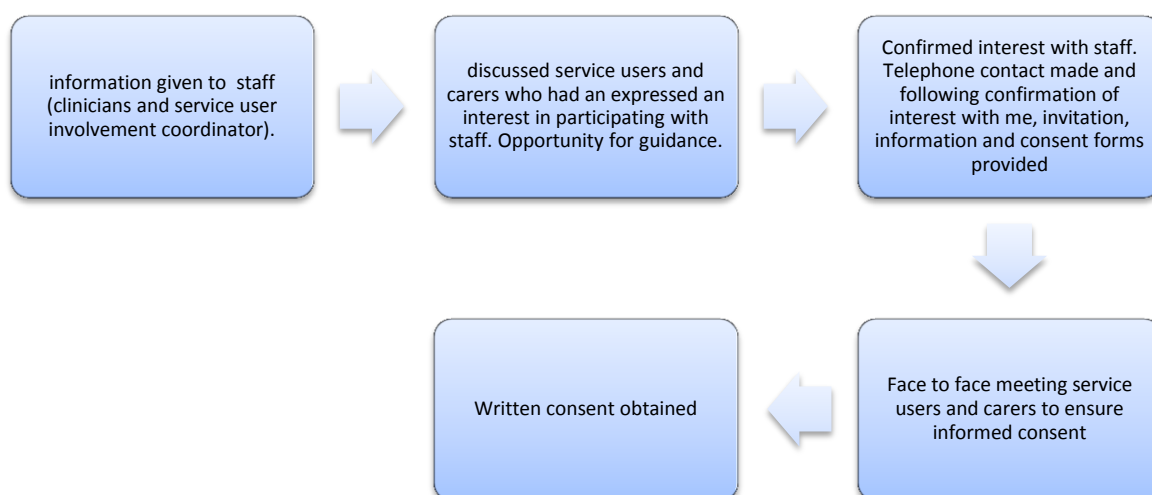
### Gatekeeping

Undertaking research in end of life care raises many ethical concerns (deRaeve, 1994) which go beyond conforming to conventional procedures for obtaining written informed consent (Payne et al, 2007). However there are ethical issues which relate specifically to the recruitment of the sample. In the first instance, I gathered a list of potential participants from our clinical information system but because of the sensitive nature of doing research with palliative care patients and their carers, I involved clinicians who worked with them in making decisions about which service users and carers would be most appropriate to approach about participating in the study. In the event, it was clinicians and our service user involvement coordinator who came to me with names of service users and carers who are interested in being part of the research. As such, they initially explained

the research with the help of the information sheet I had developed. I am aware that this sort of approach may have encouraged staff to take on a gatekeeping role which is not always helpful as it can lead to staff exercising some bias which in turn may exclude some service users who may have wished to participate (Seymour et al, 2005). However, as the same paper points out, close collaboration with the healthcare team is also an essential element in achieving the aims and objectives of any research study. The issue of gatekeeping is a complex but unavoidable issue in palliative care research. Limitations of studies are often linked to the difficulties in recruiting participants because of the gatekeeping role taken on by staff and in particular, nurses (Newton et al, 2002, Payne et al, 2007) who may perceive some patients as being too vulnerable to be included in research. While this can be viewed as staff being over protective and paternalistic, there is a positive aspect of this in that it is appropriate that staff offer patients a level of protection and as such prevent the possibility of patients feeling coerced into agreeing to take part in research. In my position as director of clinical services, there was the potential for staff to feel they should recruit participants for me as their manager. This in turn could put pressure on service users who at worst may experience a level of coercion to participate. The principle of gatekeeping then could be viewed as a preventative strategy in the management of ethical concerns that may have arisen from my position in the hospice in that staff's obligation and wish to protect patients would outweigh their wish to 'please' me.

## Recruitment process

The following flowchart (Fig. 3. 2) shows key points in the recruitment process



From the initial contact being made, staff informed me of their interest and once I had received the ethical approval I required, I then contacted the potential participants by telephone to confirm their interest. With their consent, I then provided the interested service users and carers with the approved invitation letter, information sheet and consent form (Appendices 3,4 & 5). I then met them to discuss any concerns they may have before inviting them to agree to consent to participating in my research. At all times throughout this process and throughout the data collection, I adhered to the three principles of ethical concerns in research, these being ensuring consent, protecting confidentiality and balancing the risk of harm with potential benefit (RCN, 2004). I also made it clear that participants could withdraw from the study at any point without penalty (Karim, 2000). It is also important to say that this process wasn't always quite as linear as the diagram indicates and it does not show that there were times when the process was started and that it could, and did in some cases, stop at any point.

### **3.6 The sample**

On starting my data collection, my initial sample was still developing. Difficulties of recruiting to palliative care studies are well documented (Addington-Hall, 2002) and the reality of this was reinforced to me when I was trying to recruit participants. Although a lack of time is often mentioned in terms of people being too unwell at times to participate in palliative care research, I was also struck by the service users and carers lack of time in terms of trying to fit interview times in with things like the service user's or carer's hospital appointments or meetings with social services. I was also aware then of how tired service users might be and indeed it was likely that carers would be tired as well. Many carers have their own health problems themselves to contend with (EAPC, 2009). For one couple, these were the sort of issues that eventually excluded them from being part of the study at all. As the service user's health deteriorated, his tiredness and fatigue increased as did his hospital appointments and visits from the district nurse. In the end, although the service users and carer had both consented to taking part in the study, they just did not have time to meet with me as there was always an appointment to be attended, a visit to be made or they were both just simply too tired. All in all, data collection that is sensitive to the needs of palliative care service users and carers is time consuming and labour intensive and although I felt my sample was fit for my task (Charmaz, 2006), I have to admit that the challenges of working with this group of service users and carers within the limitations of my available hours meant that there was a limit to how far I could go to achieve full theoretical saturation. The circumstances in which I was carrying out my research effectively meant that limitations were implicit.

My sample was eventually made up of married couples or bereaved spouses who had cared within the married relationship. Bearing in mind the sensitive nature of my research, it is not appropriate at this point to provide anything other than the most basic biographical details of the service users and carers who made up my sample. The rationale for this is debated further in Chapter 4, needless to say there are a number of reasons for this most of which are primarily concerned with ethical considerations. Firstly, protecting confidentiality is one of the three principle areas of ethical concerns in research (Royal College of Nursing, 2004). The use of pseudonyms is recommended in order to protect confidentiality and reduce the possibility of harm being caused to the participants by their identities being revealed (Orb et al, 2000). In observing my commitment to the participants in my research to preserve anonymity, this is a strategy which I have used. However, as Orb et al (2000) point out, in small communities such as my own research setting, even this may not be enough to prevent participants being recognised and quotations or other data from participants, even though anonymous, could reveal their identity. This aspect of my research has concerned me throughout the research process and as such, I have been determined to ensure that I take every step possible to protect confidentiality and preserve anonymity. This is in keeping with the recognition of the special considerations that need to be taken within the context of practitioner research where the researcher is undertaking research within their own organisation (Costly and Gibb, 2006). As described earlier in this chapter, there is a need for an 'ethics of care' (Costly and Gibb, 2006, pg 89) to prevail in such circumstances and doing everything to ensure that participant confidentiality is protected and anonymity preserved demonstrates a commitment to that caring ethic. Other reasons for the study not to be overly concerned with 'factual' biographical details are concerned with the interpretive nature of the

research. Charmaz (2006) encourages us to use Grounded Theory strategies to offer an “*interpretive* portrayal of the studied world” rather than “an exact picture of it” (Charmaz, 2006, pg 10) in which participants can “cast their stories in their terms” (Charmaz, 2000 pg 525). I would argue that an in depth presentation of the participants biographical details is not in keeping with a constructivist approach and it would run the risk of objectifying the participants and limiting the imaginative response of the reader. Lastly, there is something discursive about boxing service users and carers into particular categories defined by age and disease or disability (Gillman et al, 2000). This is a process that was not unfamiliar to the participants in my study and it is not one that I wished to reinforce. However, as the participants themselves refer to the life limiting conditions they have, it is appropriate to mention these as part of the biographical details provided as follows:

Of the 8 people recruited to my study, 5 were female and 3 were male. Of these, 3 were married couples and 2 were bereaved spouses. All of the service users fulfilled the criteria for care at The Oaks Hospice and as such they all had at least one life limiting illness and their needs were palliative. The service users’ primary conditions were Chronic Obstructive Pulmonary Disease, Parkinson’s Disease and Multiple Sclerosis. All of the carers had been looking after a spouse for a minimum of 10 years.

Although the make up of the sample being that of service users and carers who were either married or bereaved of the person they were caring for, was not intentional, once I had started to collect data from this group of participants, I felt that their issues were specific to them as married couples and I decided that it would not be appropriate to include participants with other types of relationships. For example, in the analysis of my data, I developed a category named ‘being

apart'. I would say that issues around 'being apart' are different for a married couple to issues around an adult child 'being apart' from a parent with palliative care needs for example. For married couples, the issues are wrapped up in marital expectation about being together which I believe this extract demonstrates. The participant is speaking about the experience of respite care,

You still want them to be happy, (laughing sadly) or as happy as they can be when you've gone away without them or you are doing something without them, because that is that's quite hard anyway. You still feel, if you leave the patient, you still feel guilty if you're doing, because you think of yourself as a couple and you feel you should be doing things together really. And of course we don't now, the illness is sort of driving a wedge between us." Lc1 (i) (656-663)

Added to this, there is little specific work about the role and impact of caring on spousal carers in the literature (Cheung and Hocking, 2004).

### **3.7 Data collection**

#### The journey begins

Nothing has made such an impact on me on my journey as a researcher than my initial interview with the first recruits to my study. After so much preparation, so much writing about what I was going to do, who I was going to recruit, inclusion and exclusion criteria, I was face to face with my first recruits. I had arranged to see this couple – a husband and wife, service user and carer respectively - towards the end of a very busy day at work. In this case, I was immediately struck by the need to adapt my pace and slow down. I was affected by a number of aspects of the meeting which I feel were markers in my development as a researcher. I felt inexperienced. After 23 years as a qualified nurse working in all sorts of environments often at a senior level, this was unfamiliar territory. Back (2002) describes how sometimes PhD students "feel a real sense of trepidation when it comes to beginning their research – particularly if this involves having to



contact 'live people' who talk back" (Back, 2002, 3.14). Also, in describing the informal interview, Chenitz confirms that it is natural, particularly in the early stages "to feel self-conscious, nervous, uncomfortable and even inadequate in the field" (Chenitz, 1986, pg 80). However, for both Back and Chenitz, they say this is not necessarily a bad thing. While Back (2002) acknowledges that he still feels like that and that it's important "just to push yourself," Chenitz explains that if recorded and analysed, these early feelings can improve the use of the informal interview and also help you to empathize with participants and how they may feel.

Added to this, I felt that I was entering a different world from my own. I became acutely aware of how *difficult* life was for this couple and what an effort it must have been for them to come to see me. I wrote in my fieldwork journal:

"Easy to talk about 'recruits' and 'samples', the practicalities of doing this are huge – people are ill.....and their lives are extremely difficult.....the sheer weight of their load – I was taken aback by it – and how my world has become sanitized."

I felt humbled and overwhelmed at the same time. The interaction brought sharply into focus the gap between theory and practice, the service user and carer and the organization, the world of illness and health. My research was giving me the opportunity to 'get close' to the issues at the heart of my work (Back, 2002) and I could feel it. This 'getting close' is where I felt I was most likely to learn and as my research progressed, develop my thinking towards the emergence of new learning and the integration within myself of the reflexive notion of the practitioner-as-researcher (Freshwater and Rolfe, 2001).

### The individual interview

Data collection was guided by theoretical sampling which is based on the need to collect more data to examine categories and their relationships and to ensure that representativeness in the category exists (Chenitz, 1986). As the purpose of a grounded theory approach is to understand the experiences of the participants in terms of attempting to see the world as they see it, data was collected by individual informal interview (Chenitz, 1986); a method that is also recommended by Charmaz (2000) in order that private thoughts and feelings should be able to emerge. In depth individual interviews are also considered to be one of the most important research tools that can be called into play when working with palliative care patients and their informal carers (Heslop, 2001).

The interview and how it is managed by the researcher seems to me to be crucially important in terms of it being an opportunity to show an acute sense of awareness and sensitivity to the participants special needs. Developing these skills is essential in terms of developing what is known as “theoretical sensitivity” (Strauss and Corbin, 1990). Theoretical sensitivity was first described by Glaser and Strauss (1967) as being fundamental to the researcher’s ability to conceptualize and formulate a theory as it emerges from the data. Once developed, they describe it as a continuous process which centres on what the researcher knows himself and of himself and also what theoretical insights he has into his research. Charmaz (2006) describes it as part of a process of looking at studied life from multiple vantage points, of comparing, questioning and establishing connections. For me then theoretical sensitivity is about being continually open to the “theoretical possibilities” (Charmaz, 2006) of the experience of learning from the experiences of others in the context of one’s own

experience. By being acutely aware of the participants needs in the individual interview, the researcher is developing theoretical sensitivity and thus opens himself up to the theoretical possibilities of the individual's expression of their experience of the world as they see it. Within this, the comfort and wellbeing of the participants must be paramount.

I was therefore flexible in terms of where the interviews took place and whether couples were seen together or separately. I felt the latter point particularly may be a concern for participants and to some extent it was. There is a practical advantage to seeing one person at a time purely from the point of view of being able to concentrate on what one person is saying without the distraction of another person being there, chipping in or maybe feeling as if they need to answer on behalf of the other. However, going through this process reinforced again that in exploring the need for respite care – which might on the surface seem so straightforward - I was exploring how people feel about each other within the context of their marital and caring and cared for relationship. This of course was a very sensitive area even for the people who had been bereaved and as such was an aspect of my data collection that required a high level of sensitivity and awareness on my part.

The following are some aspects of the data collection that I would particularly like to comment on which I believe enhanced the development of my theoretical sensitivity.

- Establishing rapport

Chenitz (1986) describes how being a nurse and using nursing skills can be helpful to the nurse as researcher. As an experienced mental health nurse, I have always recognised the importance and value of establishing rapport with service

users and carers at the beginning of a therapeutic relationship and similarly, I have felt these skills have been important in my relationship with the participants in my study. Charmaz (2006) reminds us that trying to establish rapport is a way of showing our participants respect and preserving their dignity as we proceed in our efforts to see the world through their eyes. I found this to be essential in my interviews with participants even though it could be time consuming. My first interview with Geoff at his home followed what had been a very stressful morning for Geoff and his wife Linda. Having confirmed with Geoff and Linda that they still wanted to keep the appointment with me ("this is life isn't it? You might as well see it as it is" said Linda) I noted at the time in my diary that I felt I had to "give Geoff time" to talk to me before I felt comfortable to start taping the interview with him. Even then, as with all the participants, the first part of the interview was given over to first, making sure he was comfortable and happy to continue, typically:

"..thank you ever so much for agreeing to be interviewed. You know that at any time Geoff you can just say if you want me to stop – I'll stop. If at any time you say you don't want to carry on, I won't carry on...is that okay?"

And second, asking him to tell me a little bit about how things are for him at that time including anything he wants to tell me about his illness for example and how long he may have had this condition. As well as seeing this as essential in starting to see the world from their eyes, for me, this was all about making sure the participant was comfortable and trying to demonstrate that I was interested in them as a person rather than simply a participant. To some extent, in a similar vein, this is why I wanted all the participants to have names rather than be a just a code. The names used however would not be the real names in order to protect identity and ensure confidentiality. Establishing rapport therefore was an ongoing process which included after this first interview with Geoff for example, actually spending

some time with him and his wife. Both Linda and Geoff had been very stressed at the start of my time with them that day. I had interviewed them separately and then at the end of the interviews, they seemed to come back together and they engaged me informally. I wrote afterwards

“.....we then spent 30 minutes together. Geoff brought down some of his art work from upstairs and was able to reminisce with Linda about the pop band he used to play in when he was young. She brought a book in in which he and his band were mentioned. It felt quite relaxed and the communication between Geoff and Linda was positive.”

This felt like a respectful way to end our time together which acknowledged that the research was not just about collecting the information I wanted. It was about giving something back as well.

- All data is important

Following on from the above, although all data might not appear to be strictly relevant to the study, I believe it is all important in terms of showing the participant respect by being interested in what they have to say, not being rigid and allowing data to emerge naturally, and lastly, being in keeping with symbolic interactionist principles. As such, there is a requirement to see the world from the perspective of the participant. This gives the research its context and develops our insight into how things connect for them. In keeping with this is listening to participant's stories as they want to tell them so that we might learn about their lives (Charmaz, 2006). This was Mary's response when I asked her about her husband Ron's illness. Ron had wanted to take part in the study but had died before I had a chance to speak to him about it. This was how Mary introduced me to the circumstances that led her to be in a caring role:

Mary : When he first got it, diagnosed, he was at work which was different entirely which meant that he used to come home often very frustrated because he hadn't been able to cope with ordinary things like getting his cup of tea. Having to ask for help, little mundane,

ordinary things that we don't even think about. And erm he did shake a lot in those days and then had to go into hospital to get medication.

Anna: Right, and then.... how long were you actually physically caring for Ron?

Mary: He volunteered for an early retirement, unbeknown to me he suddenly said, 'I am leaving'. The specialist wanted him to go on for another year, he thought it was good but he just couldn't cope. And it was his decision, his own decision so I let him make his own decision, it was his disease and he felt his limitations. And he was unable to go part time, which was a shame. Maybe that would have been a little bit better. But he was not allowed to do, so he also had to go from home to where he worked [names places] which was quite a journey and had to drive himself. They got a bus and that was a bit of a help but the bus refused to drop him off at the top of his road. And err, because he had Parkinson's. And I said to him 'tell them you have Parkinson's, and ask if they will' and he did and the answer was no, everybody will want the same treatment even if they haven't got Parkinson's they will all want to be dropped off at the end of their road.

Anna: Oh dear.

Mary: So we struggled, winter time on the ice and the snow when his walking became bad. I think it helped to make him make a decision to leave, perhaps before... (pauses)

Anna: He would have done?

Mary: he normally would have done, because in his head, intelligence and his experience in his job were worth something, but he was unable to carry on. (Mc1(v) lines 20-49)

I didn't actually ask for these details but for Mary, it was important for her to tell me and it was important that I heard it. The story gives me a glimpse of Mary and Ron's world as she recalls Ron's deterioration, the lack of concessions to help him, the sheer lack of understanding he experienced, the struggle to carry on and in the face of all this, making the decision himself to give up work even though with just a bit of flexibility, he might have been able to carry on. The story was told with clarity and without apparent bitterness and I felt there was no expectation within

the telling that I would necessarily respond to the injustices she was telling me about. She was simply telling me the story. I felt that these experiences would have affected Mary's view of the world and I needed to be able to see the world as she saw it. This was the sort of insight I needed to be able to analyse her words within the symbolic interactionist philosophy.

- Communication difficulties

Interviewing people with communication difficulties demands concentration and perseverance on the part of the researcher and a great deal of patience on the part of the participant. When trying to capture the voice of participants who, because of their condition, had very poor posture and could only speak very quietly, it wasn't long before I realised that if I was going to capture their voice, then I was going to have to be willing to be a bit more flexible in my approach. I had initially been quite self-conscious about using the tape recorder, holding myself in quite a stiff and inhibited way. But as the interviews progressed, my confidence grew and my initial stiffness gave way to a much more kinetic approach to my interviews in which I was happy to move around and change position in order to accommodate the needs of my participants. I think this extract from my journal captures this!

"Interviewed Geoff before [social network] map – some practical difficulties ...Geoff slipped to the floor...I moved onto the floor – with the boxer dog! I'm not sure how coherent Geoff is – communicating is difficult but I want to try and capture his voice."

The more interviews I did the less self-conscious I became and thus hopefully it became easier for participants to share their experiences with me.

As well as adapting physically, I needed to be mentally flexible in that sometimes, the data I collected didn't initially make sense in the traditional sense of the word

but in the spirit of my research design I felt that in some ways, this data was no different to any other in that I was trying to develop theoretical sensitivity and interpret and capture meaning rather than simply collect answers to questions. In this particular extract, there is quite a creative use of language

“And you rely on something you might design or make, you’ve got somebody whose selling you a package. Does it survive anywhere where it’s cosy and warm or does it just melt away?” Gp1 (ii) (181-184)

The wider context of this discussion was about respite day care at the hospice and the importance of team work. I interpreted this as being about the importance of having a sense of purpose and needing to feel safe. These were themes that Geoff came back to when talking about day hospice care.

- Being upset

In collecting data from palliative care service users and carers, there is a need to have a refined ethical awareness of when to record data and when to disregard it (Sheldon and Sargeant, 2007). I found that there were times when carers particularly became so upset about what they were talking about that they were struggling to speak. It was at times like these that I had no hesitation in stopping recording until we were both in agreement that I could start recording again.

#### Constant comparative method

While Charmaz (2006) encourages us to use Grounded Theory strategies flexibly, she makes clear that along with the researcher’s “engagement” the constant comparative method of analysis is at the core of the Grounded Theory approach. Glaser and Strauss (1967) introduced the constant comparative method as a central feature of the Grounded Theory approach and it is described frequently in



Grounded Theory literature as the concept that differentiates Grounded Theory research from other types of research design (Birks and Mills, 2011). In its Discursive Glossary of Terms, The Sage Handbook of Grounded Theory (Bryant and Charmaz, 2007) defines the constant comparative method as:

“ a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category, and category to concept. Comparisons then constitute each stage of analytical development” (Bryant and Charmaz, 2007 pg 607)

Comparisons are made continuously throughout data collection and analysis and further data collection and analysis will produce more categories (Chenitz, 1986). A grounded theory then emerges from the process of this constant comparison (Dick, 2007). And within this, data is collected not only from the participants, but from our observations, interactions and materials that we gather about the topic (Charmaz, 2006). Sheldon and Sergeant (2007) also argue that by developing reflexivity through an “active critical engagement” between ourselves and the research, the exploration of our own values and biases and where we ourselves stand in relation to the research, this process in itself becomes data. As such, in Grounded Theory, the literature we read as we collect data and analyse is another type of data, the themes of which we can use to influence the development of further categories. All of this process is linked together by the writing of memos which capture thoughts, comparisons and connections in the data which in turn helps to crystallize ideas and take the researcher in certain directions (Charmaz, 2006). Charmaz (2006) describes memos as a sort of conversation with the data. So for example, in deciding on my research question, I was already aware that there was “ a basic problem of definition” in respite care (Owen and Johnson, 2005) from the literature and also anecdotally from colleagues and service users

and carers. It seemed to mean different things for different people. This was important in terms of if it is said that there is a great need for respite care, then how do we know it's a need or what need we should be meeting if we don't have a clear definition. I was able to code different expectations of respite care and compare differing views between carers and carers and service users and service users etc. For example, respite care can mean different things even in the same interview i.e. with a carer; a need for the cared for person's symptoms to be controlled, the need for a rest, the need for the cared person's deteriorating condition to be addressed. In comparison with those expressed needs, the service user didn't actually talk about respite care as a need at all but rather about the opportunity to build relationships which he enjoyed. And so I was able to go on comparing and contrasting different views within a category of 'meanings of respite care' leading to the concept of respite care fulfilling or not different needs for service users and carers. My understanding of this was enhanced in the process of memo writing and theoretical sampling.

### Memo writing

Universally described as being crucial to the grounded theory process, memos are written throughout data collection and beyond. Charmaz (2006) describes them as the link between the researchers ideas and the stories that gave rise to them and Lempert (2007) goes as far as saying that memos are *the* fundamental process of researcher/data engagement that results in a 'grounded theory'. Records of thoughts, feelings, insights and ideas (Birks and Mills, 2011), may serve many functions but apart from anything else, they help to provide an audit trail for the research. See example below in the next section regarding relationships.

### Theoretical sampling

In a grounded theory study, theoretical sampling is a type of sampling that enables the researcher to develop the emerging categories in the analysis. The aim is to refine ideas, not to increase the size of the original sample (Charmaz, 2000)

After the first round of interviews with participants, categories had begun to emerge – “rich data can spark multiple directions of enquiry” (Charmaz, 2006) and theoretical sampling was therefore influenced by a number of factors. These included the following:

- (i) Presenting the study as an example of doctoral research at the HCES School Research Conference 2009.
- (ii) Preparing a paper for publication entitled “Does respite care meet the needs of palliative care service users and carers? Messages from a conceptual mapping” (Wolkowski et al, 2010).
- (iii) Implementing and evaluating changes in practice
- (iv) Supervision discussion
- (v) Memos

There was a gap between the first and second round of interviews which was characteristic of the interrupted process of the study as a whole. Though not always planned or desirable, this particular interruption was valuable in the sense of providing an opportunity for pausing and reflecting. The work I did and the literature I read, added to the richness of the data I was collecting and the ideas which were emerging. I will discuss this further in the next chapter as this process forms an element of the grounded theory method I have used. One of the ideas for further data collection came out of this gap in the form of feeling that I wanted to incorporate another layer of data collection in the form of a social network circle

activity. This came about as a result of discussion with my supervisors. We had agreed that it would be helpful to do a second round of interviews to follow up ideas that had been sparked off by the first but also to follow up ideas that had been sparked off by the literature and other events. We discussed models that could be used in this process during supervision. The record became a memo (see below)

Extract from memo re relationships

“The models discussed were about relationships..... Social networking theory – not just about the relationship between the carer and cared for – it’s about all networks. Need to look at what’s happening to the relationship. Go back to interviews – what’s happening to the relationship. In what ways is it advantaged or disadvantaged by respite care. In dementia care, there is a sense of identities being lost as the illness progresses but this can be transferred to other illnesses like long term conditions.

Went onto to discuss person centred care and how it’s probably inadequate in terms of relationships. What about relationship centred care? How do you do it when the people within it are inherently separate as in respite care?”

Following this, I was able to write a justification for the use of this technique. I was also influenced by the increasing body of palliative care family carer literature that was starting to highlight the complexity of the caring relationship and the importance of social and community support in sustaining relationships. I felt the social network circles exercise would enhance my understanding of the participants’ experience of this, particularly as the first round of interviews had shown much evidence of increasing social isolation. This carer was satisfied with the professional support he received but he was clear that it was not the “be all and end all”....

“The problem is, I am from a small family....so as much as I don’t like to call on anybody, erm, there are times when you’d like to talk to somebody who wants to listen and there isn’t many people who want to listen”. (Dc1(viii) lines 23-29).

So, the ideas behind the use of this tool were about giving the participants an opportunity to draw or use circles to make a picture of their relationships within their social networks with particular reference to the impact of respite care.

It was clear by this stage of the study that the issues were not only about the relationship between the carer and the cared for person but about the people and communities they were both involved in. Taking the interactionist standpoint i.e. “people exist in their relationship with others and their surroundings” (Clarke, 1999), it was clear that it would be useful to consider social networking theory.

The term ‘social networking’ was first coined by Barnes (1954) in his work on Norwegian fishing villages. He used the term ‘network’ to denote patterns of ties in a ‘community’ and although this inspired little interest initially from a sociological point of view, ‘social networks’ have since been the subject of much inquiry. Support system research has demonstrated that health is related to the availability of supportive ties (Alcalay, 1983) and indeed Alcalay concludes that social support networks and a sense of belonging are a basic human need.

Given that it is acknowledged that “caring occurs in the context of a maze of relationships and social support networks” (Clarke, 1999) this suggests that trying to understand the impact of respite care on service users and carers naturally lends itself to visual representation. While I hoped this method might be helpful to use in my follow up interviews as it may make it easier for service users and carers to explain their experiences and feelings, constructing a visual representation could in turn become part of an assessment that could be used to help to assess the needs of service users and their carers regarding respite care.

Social network diagrams have been used to help in planning care (Capildeo et al 1976) and I felt that in my attempt to understand more about how respite care affected their relationships, a visual representation could make it easier to explore this and would also give me more opportunity to interact with the participants in addition to interviewing them. For this reason, I decided not to tape the process of completing the circles but I did make note of comments that participants made while the exercise was completed. It would be another way of helping me to see their world from their perspective. I wanted them to look at the paper and be able to think, 'if this is my world, where am I in it?' Give them an opportunity to show me from their point of view. Put them more in control of the information they were giving me. Something interesting and different. Who else is in their world? Who relates to who? Who relates to what?

I was apprehensive about using this technique but I prepared myself appropriately with big sheets of paper to give people plenty of space. I bought coloured pens, highlighters and different coloured post-its with a view to them having lots of ways to express themselves. In practice however, all participants appeared reluctant to use the materials themselves and were happy to direct me as to where things should go. All of the participants though were happy to take part in the exercise and although I didn't tape the interaction around the completion of the exercise, I made notes on the circles and the activity did give rise to the expression of some interesting insights into the nature of caring, relationships and the impact of life limiting illness and disability on lives and relationships.

I had decided on providing a basic template of four circles and I put the couple in the middle of the circles. I explained to participants that I would like them to use the circles to try and provide a visual representation of their relationships

particularly in relation to the caring/receiving care/supporting relationships and within that who or what were the most important aspects in terms of supporting them and their relationship. This is probably why I put the couple in the centre. In the same way that respite care supposedly addresses the needs of the 2 people – the relationship.

There is evidence to show that a social network diagram can help in planning care (Capildeo et al, 1976) for patients who have had strokes. This was of interest to me as the diagram allowed the patient's social environment "to be seen in detail at a glance". Bearing in mind the burden of seemingly endless assessment and questioning when service users and carers are trying to access services, this would surely be a useful tool.

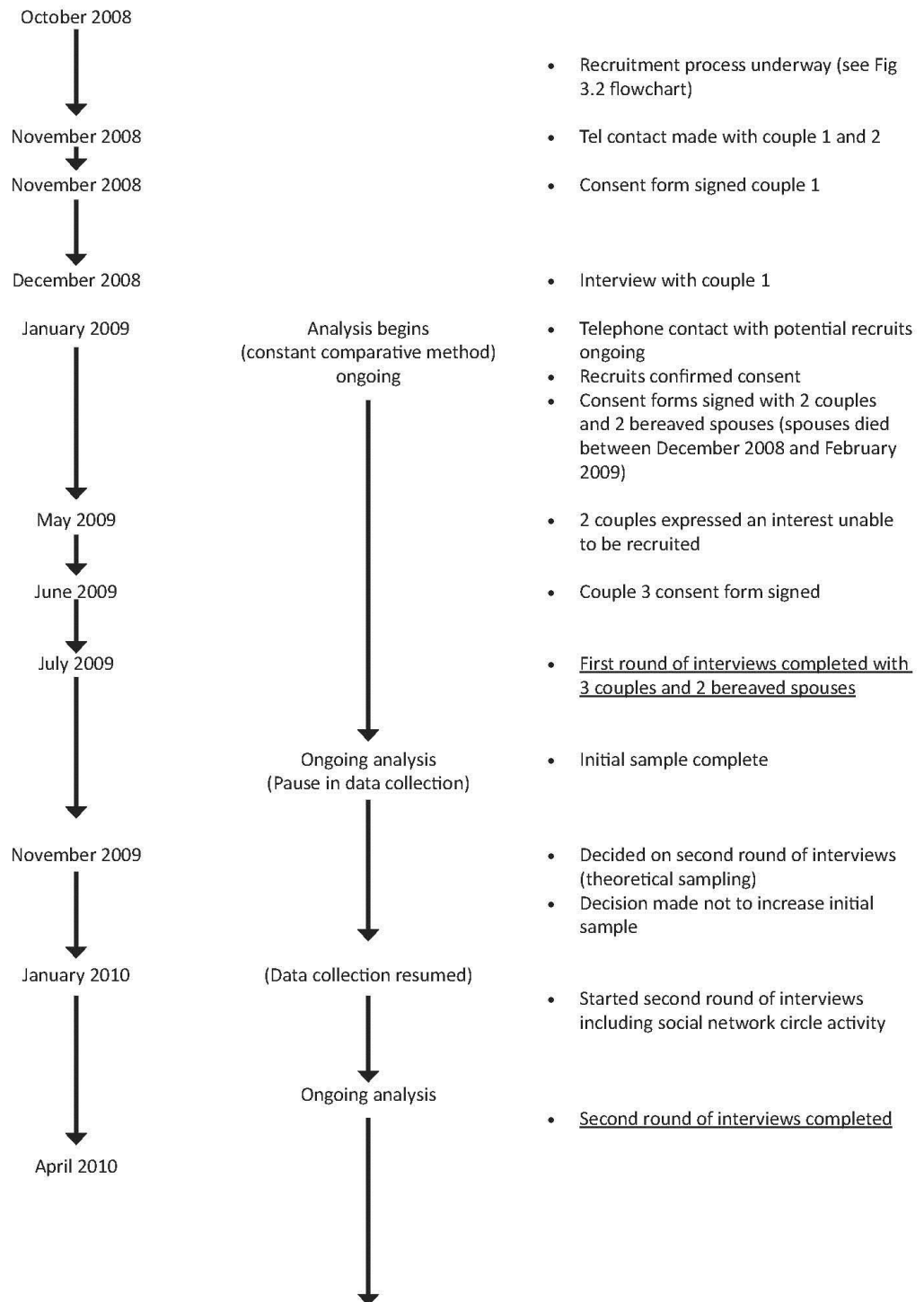
This method was used to enhance the possibility of understanding better the nature of the caring relationship and how it sits with and is affected by other relationships within the social networks of the service users and carers who are participating in this research. There is already evidence that diagrams can be useful in making complex arrangements easier to understand and as such, using this method is respectful of the complexity of the caring relationship and the relationships that surround it. In turn, I believe it has enhanced my understanding of the potential of relationship centred care.

### Timeline showing sequence of research process and data collection activities

The following diagram (Fig.3.3) is a timeline which shows the sequence of the research process and data collection activities from November 2008 (telephone contact made with first recruits to study) through to April 2010 (all interviews completed). Analysis was ongoing from January 2009 and continued after the second round of interviews was completed in April, 2010. This sequence is developed further in Chapter 5 in a more detailed diagram (Fig 5. 1 The process of analysis: an application) which shows how data collection in the form of the individual interviews followed a linear process which was at the core of my study. It also shows how, at the same time, much was happening around this core in the form of many influences which generated an interplay of ideas around and within it. For Fig. 3.3, please see below:



**Fig 3.3 Timeline Showing Sequence of Research Process and Data Collection Activities**



### Data management

Electronic records of transcripts are being stored safely on my computer at the hospice where I work and on an encrypted memory stick both of which are secured by two different personal passwords. Any paper records are being stored in a locked filing cabinet. In keeping with the hospice's records policy and in line with Northumbria University's Research Data Management policy, all records of the research will be kept securely for a period of 8 years after which they will be destroyed.

## **Chapter 4 Ethical considerations**

### **4.1 Introduction**

“The basis of ethically sound nursing research lies in the relationship between the researcher and participants. However, it is also obvious that the content, the process, the methods used and the ethics of the study cannot be divorced from this or from each other” (Kylmä et al, 1999, pg 237).

Kylmä et al's (1999) Grounded Theory study on the dynamics of hope in HIV-positive adults and their significant others recognises the importance of ethical considerations in research with vulnerable people. However, what this reference makes particularly clear is that ethical issues in such research do not fit neatly into a chapter or a particular section of a study; rather they are part of every aspect of the research and as such, a sense of ethical concern should permeate the whole work demonstrating “a vigilant and reflexive stance” being maintained throughout the research engagement (Seymour and Ingleton, 2005, pg 138).

Similarly, although research guidance (Royal College of Nursing (RCN) 2004) reinforces the importance of careful adherence to the three principle areas of ethical concerns in research which are ensuring consent, protecting confidentiality and balancing risk of harm with potential benefits, it is widely accepted that in qualitative nursing research particularly, there are specific ethical challenges (Chenitz, 1986, Ramos, 1989, Seymour and Ingleton, 2005) which require a high level of sensitivity and self awareness. Along with the more general ethical challenges associated with palliative care research, this chapter will be devoted to exploring these issues in the context of my research journey and developing reflexivity.

## **4.2 An ethical context for palliative care research**

The general ethical challenges of carrying out research with palliative care patients are well documented (Hill and Penso, 1995, Karim, 2000, Rees, 2001, deRaeve, 2004, NICE, 2004, Seymour et al, 2005) and within this, there is particular concern for the issues around consent:

“Patients requiring palliative care may fear they need to give something back to their carers in order to show their gratitude for the care they have received. Researchers must be careful not to take advantage of this”. (Rees, 2001 pg 490).

The concern being that because of a keenness to show how grateful they are for the care they have received, there is the potential for service users to agree to participate in research if they see it is an opportunity to demonstrate this gratefulness. Especially when the research is taking place in the setting in which service users are being cared for or on which they depend, it could be said that while consent maybe freely given, it may be unduly influenced by the situation and therefore not truly informed (Seymour and Ingleton, 2005). In planning my research, my aim was to be sensitive to this issue. The reader may recall how in Chapter 1, I described my practice vision for the hospice where I work which was to develop a listening culture in which service users and carers were properly involved in the evaluation and development of services provided by the hospice. One of the challenges of service user involvement in palliative care is the issue of gratitude (Hodgson, 2007) for similar reasons as described above. The need to be grateful could be said to be linked directly to power differentials between staff and service users. Therefore, in terms of minimising the potential for ‘gratefulness’ certain strategies were put in place in order to promote a sense of equalness that would hopefully empower service users to feel free to challenge, express concerns or simply share thoughts or suggest ideas. The strategies were based on a variety

of initiatives including supported meetings with an open agenda and no authority figures being present (Service User Forums) but also specific groups (building meetings, feedback meetings, the Listening Day) where service users and carers had the opportunity to sit together with the Chair of the Board of Trustees and the Chief Executive for example, to discuss decisions and issues that may affect them and the environment in which they were being cared for. I believe this has encouraged an atmosphere where the principles of critical practice ie “respecting others as equals” and having an “open and not knowing approach” are promoted. In terms of the issue of consent to participate in research, while not being complacent about the potential for consent being based on gratitude, I believe that a culture which encourages service users and carers to actively participate in their care and comment on the service they are receiving is less likely to make people feel they have to agree to everything purely out of gratefulness for their positive experience of being cared for. In conclusion, I felt my practice vision was as near an ethical foundation for my study as it could be and from speaking to service users and carers, I felt reassured that I had gone at least some way to ensuring that consent was given in a free and informed way.

#### **4.3 Developing an ethical framework**

When I reflect on carrying out my research, I feel it is unlikely that I will ever be able to fully capture in my thesis the ongoing sense of ethical concern for the participants and the feeling of responsibility towards them in terms of making sure that their voice was heard and that the study would make a difference. On reflecting on the relationships that I was building with participants, I wrote at the time: “I feel this huge sense of responsibility. I feel participants are trusting me and I want to get it right”. I think this captures my ongoing ethical concern for the participants and it also highlights the importance of the researcher having support

(Seymour et al, 2005) which I felt I had through regular supervision from my supervisors at the university. I also did find it helpful to keep a diary of my experiences and feelings.

It strikes me now how important it was to have an ethical framework within which to address the ethical issues in the study (Seymour and Ingleton, 2005) some of which I expected and planned for and some of which took me by surprise. The importance of an ethical framework which fits with the design of the study and the values of palliative care is made clear by Seymour and Ingleton (2005). Their model which describes “values underpinning research design” eg a collaborative and cooperative activity between the researcher and the researched, and “parallel principles in palliative care” eg palliative care is seen as a collaborative and cooperative activity between carers and those who are cared for, helped me to understand how the theoretical underpinnings of my research could provide the ethical framework needed to conduct my research in an ethical way. I feel that the theoretical underpinnings of my research being learning from the experiences of service users and carers, embracing the principles of critical practice and learning through ‘relational endeavour’ not only provided an underpinning philosophy but also an ethical code. I mean this in the sense that inherent in the underpinnings are ethically sound values such as respect, learning and collaboration, all of which encourage a thoughtful and sensitive approach at the same time as being at one with the principles of palliative care as described by Seymour and Ingleton (2005). While certainly not providing all the answers, having an ethical framework allows one to make sense of the issues and respond reflexively.

#### **4.4 Ethical and methodological issues**

It is widely accepted that the best way to address ethical issues is to prepare for them as much as possible by giving thought to the special needs of the particular participants (Seymour et al, 2005), being aware of potential difficulties (Ramos, 1989) and by making sure arrangements are clear (Chenitz, 1986). This is particularly important in situations such as mine whereas the researcher, I am also a nurse and a manager of the service. The following are some of the ethical and methodological issues I identified, tried to prepare for and addressed when necessary. The reader will also find ongoing references and reflections on ethical issues woven within the thesis as a whole.

##### Power imbalance

As director of clinical services of the hospice where I work and where I have collected the data for my study, there was a need for me to reflect on the effect my position may have on the way participants responded. No matter how much I feel I may have done to present myself as 'researcher' rather than 'manager', I think it would have been naïve of me to think that my role in the hospice might not potentially affect the outcome of my interviews if not properly managed. I have already discussed how my role might have influenced recruitment of participants and I have mentioned strategies for addressing this, however, similar issues may well have affected consent and in turn data collection in this situation. In studies like mine, there is a danger that people may think they have to consent to participating because they feel they may be disadvantaged with regard to accessing services in future if they don't. Alternatively, they may feel that if they participate, they will actually be treated more favourably than those that don't. These concerns may carry over into the interview. Holloway and Fulbrook (2001)

describe how the status of the interviewer may have an impact on participants' responses – particularly if the interviewer is regarded as an 'expert'. As the manager of the service, there was a danger that I may have been seen in this sort of light.

“Thus participants may respond in ‘the right way’ or say ‘the right thing’ because they want to be perceived in a favourable light – the ‘halo’ effect. As such, there is a possible tendency to misrepresent their true thoughts and perhaps avoid contentious issues, or understate negative feelings”. (Holloway and Fulbrook, 2001 p 548)

Reinforcing that there are no clear cut answers with regard to this issue, the importance of the study's Information Sheet is highlighted. The Information sheet is an opportunity to address some of these concerns. For example, the following is a short extract from the Information Sheet:

**“What happens if I do not want to participate in the study?**

You are entirely free to decide whether you want to be involved or not. The decision you make will not, in any way, affect the care you receive at the hospice.

**What happens if I agree to participate in the study and then change my mind?**

You will be completely free to change your mind about participating at any time. The decision you make will not in any way affect the care you receive at the hospice” (Information Sheet for participants).

The Information Sheet provides an opportunity to answer the questions participants might have which are so crucial to their situation but they may feel unable to ask. Because I knew that there was a chance that service users and carers may feel under pressure to participate, I was able to use words and phrases



that reinforced their autonomy and freedom to choose eg “you are *entirely* free to decide...”, and “the decision you make will not *in any way* affect the care...”. I also took opportunities to reinforce the Information Sheet verbally.

Similarly, the second part of the extract emphasises the ongoing nature of gaining consent (Holloway and Fulbrook, 2001, Rees, 2001). Again, the choice of language emphasises the desire for participants to feel free to change their mind “*at any time*” without penalty and once into the data collection, I offered the opportunity to stop participating on several occasions (Seymour and Ingleton, 2005).

#### The need to deliver a service

As well as a manager, I am a nurse and as I explained earlier in this chapter, this has potential ethical implications for research. I am able to acknowledge that when I am talking to service users and carers, I feel more like a nurse than a manager. Although a manager, I am primarily a nurse and I am aware that my interactions with service users and carers are underpinned by my identity as a nurse which is far more than a role – it is part of my being. Chenitz (1986) describes the advantages and disadvantages of having this background. It can be useful for the nurse researcher in gaining the confidence of informants who identify nurses with caring and nurturing and Chenitz says (1986), “The trust subjects have in nurses and nursing can be transferred to a nurse in a research role” (Chenitz, 1986, pg 85). However, there may also be an expectation that the researcher can intervene for service users and carers or with them and Chenitz (1986) cautions nurses to be careful wherever the nurse identity is used “that you are not implying that you are there in your clinical role” (Chenitz, 1986, pg 86). Emphasising the importance of reflexivity, Chenitz recommends that whenever the nurse researcher is aware

that the nurse role is being used, the nurse should ask herself “Am I uncomfortable as a researcher? What is happening that is making the research role uncomfortable?” (Chenitz, 1986, pg 86).

Again, the Information Sheet is crucial in stating the nurse researcher’s position:

**“Who is the researcher?”**

I am Director of Clinical Services at The Oaks Hospice, and I am very interested in how we provide respite care. However, I am doing this research as part of my doctoral research at a (named) University. As such, it is important that participants understand that generally speaking I will not be able to respond directly or ‘intervene’ in concerns a service user or carer may express about services provided by The Oaks Hospice during the interviews. Any concerns about the care provided by the hospice should be addressed through the normal channels.” (Information sheet for participants)

While essential in helping to prevent calls to intervene, it is acknowledged that resisting “the old call to deliver service” (Chenitz, 1986, pg 86) is a struggle for nurses and I can certainly recognise that in myself and in my own experiences in the study.

The importance of clarity

I believe that within all of this, it is impossible to predict all of the ethical issues that may arise through struggles with role and participants expectations of the nurse researcher. For me, it was something that I was continually aware of and for the most part it was a positive thing in that I felt that being a nurse did help me to develop a rapport with the participants and have an empathic and nurturing relationship (Seymour and Ingleton, 2005). However, that feeling did leave me feeling uncomfortable at times because I did want to provide that service which

Chenitz (1986) refers to and I still reflect on how I and the relationship I developed with the participants was perceived by them ie did I fulfil their expectations of me? The importance of the information provided in the Information sheet cannot be underestimated. The following extract shows how while making my role in the research clear, it does not deny my nursing background but frames it in a way that shows the part it plays in the work I am doing:

### **What course is the researcher studying?**

I am studying for a doctorate of nursing science. This qualification is called a professional doctorate in that it is about practice rather than theory and in order to achieve it, I have to show that I am developing practice. By doing this research, I am using the skills that I have developed over many years of being a practitioner in order to learn from service users and carers to develop practice that reflects this learning (Information Sheet for participants)

I feel this information does make my role clear and it reflects my ethical framework and so whatever struggles with this I had 'in the field' as it were, I could refer myself back to this and hopefully convey this clarity to the participants in the way I presented myself and responded to them.

It is clear therefore that in my role as nurse researcher, it would not have been appropriate for me to 'intervene' as a manager or a nurse but, as Seymour et al (2005), explain, there are times when as a nurse, researchers have no choice but to intervene eg when a patient may be at risk from harm. In such a situation, the role of objective researcher may be impossible to ethically maintain and one may have a duty to intervene (Seymour et al, 2005). This did happen to me on one occasion during my research and as such, there was no struggle involved in what I needed to do. I wrote in my field notes at the time that I had visited the participants

as planned but had found one of them to appear very stressed and the other quite subdued:

“Before I started the interview, I felt concerned enough to ask them about the support they were currently receiving from the hospice because it was clear from what had been said to me that a higher level of intervention was necessary. I got their permission to discuss with the team re possible referral for emergency respite/family support team intervention”

Interestingly, the carer asked me if this was ok as she had remembered I had said from my notes, “that my researcher role was separate. I said that it was but that I couldn’t not hear what I was hearing or not see what I had seen” and that I had a duty with their permission to pass this onto my colleagues. They were both happy for me to do this.

Most problems that may arise though are not so clear cut and therefore “maintaining a self-reflexive stance is imperative” (Seymour et al. 2005 pg 182) and as they go on to point out, the way one deals with such problems has the potential to enhance rather than detract from the quality of data the researcher collects.

On the whole, ethical issues that arise from the researcher having different roles can be minimised through ensuring that arrangements for the research are laid out clearly from the beginning. In this sense, the Information Sheet could be said to be a sort of ethical preventative strategy. However, there is always a danger that once the interviews have started, this sense of clarity may be lost and I did find sometimes that I reverted to a communication style that was more in keeping with my role as manager at the hospice. This may have had an effect on the data I collected. In order to attempt to prevent this, I reinforced the information in the Information Sheet through my appearance and behaviour. When interviewing, I wore less formal clothes than I do as a manager and most importantly, I didn’t wear my badge. In fact, I did have another badge made which I wore which said

'Researcher'. As superficial as it seems, I think this did help me to think and behave differently and my perception was that it did help participants respond to me in a different way. As well as promoting clarity, it also gave the message that I was a student and was learning from them. This is very powerful in terms of developing a culture of critical practice and ultimately, I am hopeful that in spite of any struggles with clarity and roles, I was presenting myself as someone who did have expertise but did not have all the answers. This in turn hopefully helped to guide people to an understanding of me as a manager who through learning from them is working towards a role where theory and practice, researcher and manager, are combined which in turn will affect the quality of care they, and those who come after them, will receive.

#### Protecting anonymity

Before signing the consent form to confirm her participation in the study, one of the participants asked "will I be able to see what you've written?" I brought this question to supervision to reflect on my response and to seek guidance on the issues that arose from it. The participant's concern was how I might interpret what they might say in an interview. I felt this question related to the ethical commitment to protect anonymity and as such my response was that I would be happy to share what I had written with them although I made it clear that their identity would be protected in the report so they should not worry that they could be identified by what they had said. Having said that, as discussed in Chapter 3, it is acknowledged in the literature that while the researcher may do their best to protect identity (Holloway and Fulbrook, 2001), it can be extremely difficult to mask individual responses in certain situations (Archbold, 1986). In Chapter 3, I describe the special considerations that need to be adopted within the context of

practitioner research where the researcher is carrying out research within their own organisation as I have done. In situations like this, Costly and Gibb (2006, pg 89) explain that there is a need for an 'ethics of care' to prevail and doing everything to ensure that participant confidentiality is protected and anonymity preserved demonstrates a commitment to that caring ethic. As I reflected on these ethical issues, it struck me that as Reed and Proctor (1995) describe the practitioner researcher as "an insider" undertaking research in their own setting as opposed to "an outsider" being the researcher with no professional experience of the research setting, as part of my 'ethics of care' it was appropriate to acknowledge that I was writing for what could be described as two audiences – an "insider" audience being service users, carers and staff from my own organisation and the research setting, and an "outsider" audience being those who have no experience of my organisation and the research setting. With careful adherence to ethical concerns as outlined in research guidance described above (RCN, 2004), the risk of participants or situations being recognised by an "outsider" audience would be minimal if not entirely non-existent. However, because with the "insider" audience the risks of a participant or situation being recognised are naturally much greater, it was essential that I developed an ethical code of conduct where the ethical risks associated with the "insider" audience were the primary concern. As such, this notion of two types of research audience reinforced the importance of the need for special "insider" audience ethical considerations being fundamental to a study carried out by an "insider" researcher. I adhered to these considerations through employing a number of strategies. These included using a fictitious name for the setting in which I carried out the research throughout the main body of the thesis, references and appendices, using pseudonyms for the participants' names and by providing limited participant biographical details only.

On reflecting on the issue of protecting anonymity in supervision, it became clear that as well as protecting identity, there was another ethical issue within the participant's request "will I be able to see what you've written?" which I found was a big question in qualitative research – who owns the data? Whose data is it? It would not be an issue for a more traditional positivist researcher who would be content to collect the data they required from their research subjects and then make it their own as it were with the subject having no further involvement. It struck me that this participant's question drew me back to ethical concerns around power and how being prepared to reflect on this and show I had thought about it was in keeping with the philosophy underpinning the research and my ethical framework. Whereas a positivist approach might be said to deny humanness and thus deny the voices of those involved from being heard (Sargeant, 2004), an interpretive perspective would inform research that confirms humanness and actively seeks the voice of the participant. Thus, it would be acceptable for me to share what I had written with any of the participants to the extent that they could even be involved in the analysis. However, even if I did not go as far as to involve participants in analysis and I didn't, it would still be important for me to ensure with them that I had heard their voices correctly.

The way to do this would be through letting participants read what I had written about them (Holloway and Fulbrook, 2001). Strauss and Corbin (1994) themselves in explaining the grounded theorist's responsibilities and uses of theory state that grounded theorists "owe it to our 'subjects' to tell them verbally or in print what we have learned, and to give clear indications of why we have interpreted them as we have" (Strauss and Corbin, 1994, pg 281).

I have thought about this a great deal over the course of my research and while I initially thought that it would be important to share my interpretations of this

participant's words with them as soon as I was able to, I believe now that this showed an immaturity in my understanding of the Grounded Theory process and a naivety about how, through coding, the words of the participants would become increasingly conceptualised and theoretical. This maybe a limitation in my thinking and understanding of Grounded Theory but once into data collection and analysis, I realised that simply sharing the words I had collected from the participants with them would be at best a checking process and at worst it would be meaningless and confusing. This is because understandings of the participants' worlds in Grounded Theory are based on the theoretical interplay between the researcher and the researched as they develop an increasing theoretical sensitivity and progress towards theoretical saturation and the development of increasingly theoretical concepts. As such, reflecting in supervision on this request led me to feel most comfortable with the plan of writing to participants on completion of the thesis to offer them the opportunity to receive a summary of the study (Lee, 2009) and for me to talk about it with them in accordance with their wishes and in a way that is most comfortable for them.

#### **4.5 Developing reflexivity**

Probably the best description of reflexivity I have come across is as follows:

“There is no one way street between the researcher and the object of study; rather the two affect each other mutually and continually in the course of the research process.” (Alvesson and Skoldberg, (2000), pg 39)

In professional doctorates, it has been suggested that the process of learning is at least as important as knowledge outcome (Lee, 2009). As such, the development of reflexivity which seems to personify the dual learning processes between the researcher and the researched, the practitioner and the researcher, the theory and



practice, must be said to be crucial. The development of reflexivity then is also a mark of a heightened ethical awareness that is evident in the researcher's ability to demonstrate their involvement in the research process itself and a transparency in the way they approach this and how they conduct themselves within it.

It would seem straightforward to say that putting strategies in place to 'distance' myself from my professional role would be helpful in terms of providing clarity for participants in terms of expectations. However, I have already shown that there were occasions in my research when 'distancing' was not entirely possible and in many ways, I believe that much of my learning and my development as a reflexive nurse researcher has come about and continues to do so as a result of the duality of my role and the fact that my study is based in practice as opposed to theory. At one point in my field work notes, I comment that I feel that during one particular interview with participants in the study, that I am getting close to the issues at the heart of my work (Back, 2002) and I can remember feeling this strong sense of connection with the participants but more than that, a sense of connection with the process which was occurring between us. This is not necessarily a comfortable place to be indeed probably the opposite, as this is where this sense of researcher and participants being what I would describe as actively open to each other is taking place. This is where there is the most need for the researcher to allow themselves to be part of the process but at the same time retain a high level of self-awareness and ethical sensitivity. A reflexive position is therefore not one that is clean and clear cut rather it shows a willingness "to leave the high, hard ground inhabited by academics and go down into the swamp where practitioners go about their daily work" (Freshwater and Rolfe, 2001, pg 527) where lack of clarity and the need for flexibility and adaptability is a given. There is an inherent uncertainty about being in this position and as Cook (1998) points out, this means being

prepared for what she refers to as “messiness” as it is within this uncertainty that theory and practice are most likely to meet. She therefore refers to “mess” as a “very highly skilled process” (Cook, 1998, pg 103) where one needs to hold oneself to allow learning to take place.

Therefore, far from palliative care research which involves primarily face-to-face methods being simply about ‘just talking’ or ‘just observing’ without potential to cause harm (Seymour et al, 2005, pg 180), in developing reflexivity, there is a recognition of the full implications of the impact the researcher, who is a practitioner, has on those who are being researched. As Arber advises us:

“It also means that a researcher with such a background should interrogate their own beliefs and feelings in the same way that they interrogate those of others.” (Arber, 2006, pg 156)

She suggests keeping a field work journal as a strategy for enabling reflexivity and as such, recording my own thoughts and feelings and emotional responses to research situations has, I believe, helped me to become more reflexive and within that more ethically aware and sensitive to the needs of the participants and where I sit as the nurse researcher within the research process.

## **Chapter 5 Analysing and interpreting the data**

### **5.1 Introduction**

Data collection in the form of the individual interviews took place over 14 months and data collection in the wider sense in terms of for example discussion with colleagues, supervision, memo writing, keeping field work notes and keeping up to date with the literature, happened concurrently and beyond the direct work with the participants. This period has covered approximately 24 months.

Analysis has been ongoing from the first interview to the present time. This has been an interrupted process but while analysing during data collecting wasn't always possible in the strictest sense, internal constant comparison was happening throughout and interviews that followed on were influenced by the interview that went before. Also, I have returned to the data continuously within this time which is in keeping with grounded theory analysis. Charmaz (2006) recommends that we should return to our data again and again as we learn from studying it. This is also necessary for the categories to become more theoretical. Another important way in which this happens is through the process of memo writing.

Theoretical sampling and the development of concepts was influenced by emerging themes from the first round of interviews, ongoing literature review and practice developments. Theoretical saturation was achieved following the second round of interviews which included the completion of the social network circles activity as described in Chapter 3.

## **5.2 The process of analysis**

One of the reasons I was drawn to Grounded Theory was because it was about developing a theory that would be useful. I liked the idea of this very specific type of analysis, which was going to take me above descriptive analysis to a much more theoretical level in the development of concepts. These concepts could then be integrated in order to provide a theory that would illuminate the social processes involved in the experience of respite care and hopefully then provide a platform for service development and improvement.

To get this fresh understanding that was going to be useful, I was particularly attracted to the process of analysis in the application of Grounded Theory. It seemed to me that the process would enable me to become really close to my data and allow me to make the most out of every word. This was important to me on a number of levels. I knew from the literature that recruiting to my sample was likely to be difficult because of all the well documented practical, methodological and ethical issues concerning doing research with service users who have palliative care needs and their carers who are trying – often against all odds - to meet those needs. In reality, it was indeed very difficult, and for the service users and carers who had been willing to give me their precious time and had made such an effort to be able to contribute to what they perceived as an opportunity to make things better for people, I felt a great sense of responsibility. I was reassured by the meticulous attention to detail that was required in Grounded Theory analysis and I felt that if I could do this well, I would indeed be doing justice to the wishes of the service users and carers who were willing to welcome me into their worlds in such difficult times.

It was with much enthusiasm that I embarked on this part of my journey only to find that I was unexpectedly daunted by the apparent enormity of what was required.

As described in Chapter 3, the constant comparative method of analysis in Grounded Theory is what sets it apart from other methods and within this, coding is seen as equally important (Holton, 2007). It felt very important to get this right, but it seemed that the nature of what I was attempting to do didn't lend itself to a particularly linear process. Diagrams are considered to be central in Grounded Theory work (Lempert, 2007) in helping to bring order to the data and further the process of analysis. As such, I created a diagram to help me demonstrate the process of my analysis.

Fig 5. 1 The process of analysis: an application

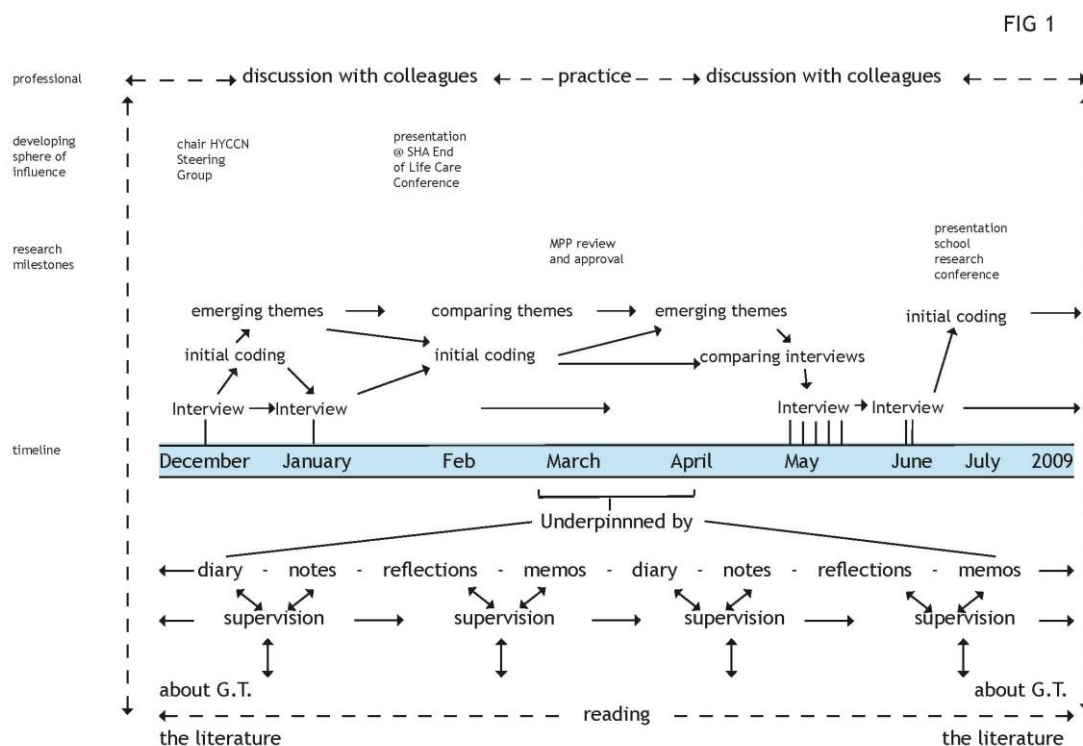
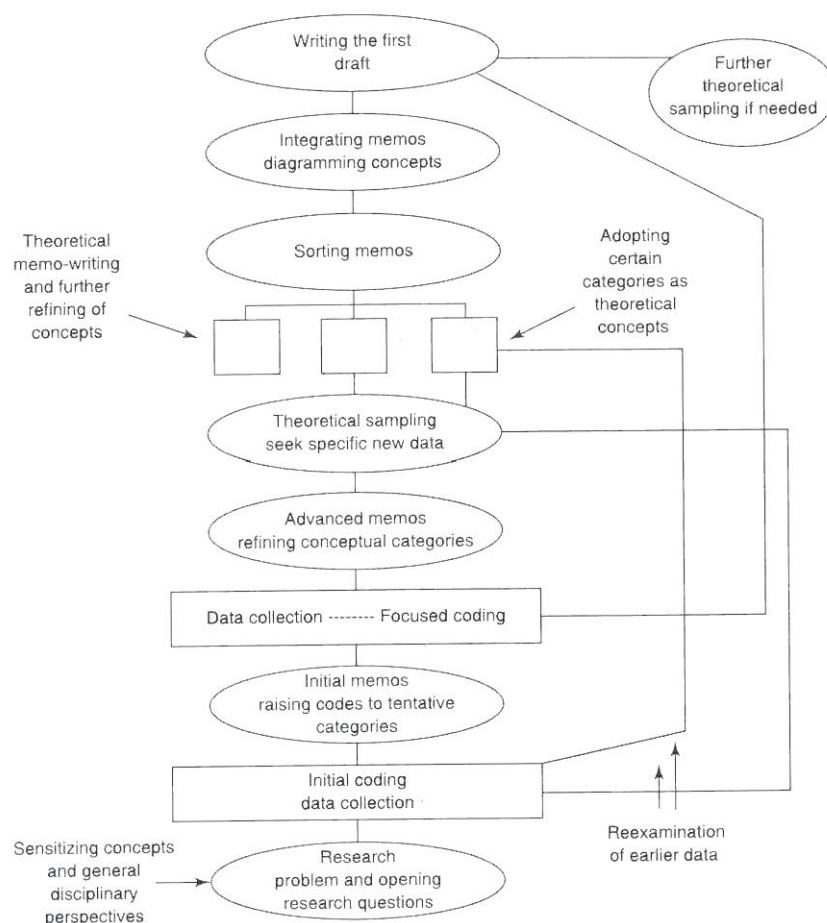


Fig 5.1 attempts to illustrate this. Although data collection in the form of the individual interviews followed a linear process, much was happening around what I considered to be the core of my study – the interviews - and there were many influences which generated an interplay of ideas around and within that core. I use the example of an 8 month period from December 2008 to July 2009 from the first interview onwards which was typical of how the study period progressed as a process that was interrupted by events and milestones but framed by the continuity of reading, practice, discussion and supervision. The dotted line frame illustrates that the picture always had the potential to be, and often was, influenced by events which were external to this activity, such as personal experiences. Some of the tools of Grounded Theory in the form of notes, reflections and memos are also there hopefully showing a growing reflexivity in the study and helping to join it all together. I believe that as a whole, this is a positive diagram which demonstrates Charmaz' view (2006) that in Grounded Theory, data is collected not only from the participants but from many more sources. However, actually being 'in it' was a bit overwhelming at times and I often worried about how I would pull everything together. It helped to find that I was not alone in feeling like this. Data analysis in Grounded Theory has been compared to doing a jigsaw puzzle without having the picture to look at (Pearson, 1991, Coyne and Cowley, 2007) and without any readily available guidance on how to produce categories from the raw data (Pearson, 1991). Heath and Cowley (2002) acknowledge that there is often a 'doing it right' anxiety about using Grounded Theory which gets in the way of the experience of actually doing it. But it is actually in the doing of it where we learn how to do it. My feeling was that it was probably ok to feel unsure about how to progress but I needed to look to a Grounded Theorist whose work I could identify with and which could provide me with some direction that would help me to fit the

pieces of my jigsaw puzzle together. In Chapter 3 I described how Charmaz' approach (2006) was in keeping with the theoretical underpinnings of the study. It was with this in mind that I turned to Charmaz again for a template that would help me to develop my craft (Charmaz, 2006) and ultimately do justice to the Grounded Theory process and most importantly, the words and actions of the participants in my study. While experiencing my position as demonstrated in Fig 5.1, I found it helpful to look to Charmaz' diagram (Fig 5. 2 Charmaz, 2006 pg 11) of the Grounded Theory process in order to keep me on track and help me to make sense of the data I was collecting.

Fig. 5.2 The Grounded Theory process (Charmaz, 2006, pg 11)



### **5.3 The coding process**

In Chapter 3 I described how my research was giving me the opportunity to 'get close' to the issues at the heart of my work (Back, 2002). In turn, I feel that the Grounded Theory analysis process reinforces and enhances this opportunity through its coding process. The coding process in a Grounded Theory study is made up of at least 2 main phases. An initial phase involving naming each word, line or segment of data, followed by focussed coding. This is a selective phase which uses the most significant or frequent initial codes to sort, synthesize, integrate and organise large amounts of data (Charmaz, 2006). Through the use of constant comparison and memos, categories are developed and concepts emerge. For me, as for many others, (Charmaz, 2006) line by line coding became the first step in the Grounded Theory process. Although there are many reasons why Grounded Theorists choose to code in the way they do, I felt that line by line coding was in keeping with the theoretical underpinnings of my research in the sense that staying so close to the data would give me the best opportunity to genuinely explore the participants' experiences and perspectives of respite care. This was a particular concern as because respite care is such a taken for granted concept, unless I paid very close attention to the detail of the data, there would be a danger that I would only be likely to uncover superficial meanings when my aim was to provide a fresh perspective on a subject that although very familiar, is poorly understood and problematic. However, as in data collection, analysis in Grounded Theory is not just about analysing the interviews as Fig 5. 1 demonstrates. As such, the following description of the coding process will aim to demonstrate how all of the data was analysed in the context of the constant comparison process. The examples given come from the period of January to



September 2009. Through these examples, in the same way as Grounded Theory aims to capture a slice of the phenomenon being studied through the eyes of those who are experiencing it in their worlds, so I hope the examples capture a slice of the process of analysis through my eyes.

#### **5.4 Actions and processes**

Charmaz (2006) gives us “a code for coding” as follows in order that we may be guided through this initial stage of analysis.

- “Remain open
- Stay close to the data
- Keep your codes simple and precise
- Construct short codes
- Preserve actions
- Compare data with data
- Move quickly through the data”

I found this useful as it emphasises the importance of actions and process (Glaser and Strauss, 1967) in Grounded Theory analysis. Although Charmaz (2006) encourages us to use Grounded Theory strategies flexibly, it seems to me that although this flexibility moves us away from the idea of seeking to discover *the* basic social process in our research, in our attempts to capture the experiences of our participants as they experience them in their worlds, there is still a requirement that we should think in terms of social processes. As such, in keeping with classic Grounded Theory (Glaser and Strauss, 1967) action and process can be reflected in the way we collect and analyse our data. Morse (2001) explains the significance

of process in Grounded Theory and how inviting participants who have experienced the phenomena being studied to “tell their stories” is best suited to Grounded Theory data. In keeping with this emphasis on process, the use of gerunds – verbs as nouns which end in ‘ing’ - in our coding remains fundamental to a Grounded Theory study (Morse, 2001, Charmaz, 2006).

## 5.5 Initial coding: analysing line by line

Fig 5.3 is an example of line by line coding from my analysis. In this extract, Linda describes what happened when she was suddenly taken ill and consequently was unable to care for her husband Geoff who has cancer and Parkinson’s Disease.

Fig 5. 3 Line by line coding

Line by line coding	Transcript
Telling the story. Being taken ill Respite care having to be found for Geoff Social services having to find this quickly Not being able to look after Geoff Not having choice/control Geoff went to NH2 Social Services having trouble finding somewhere where Geoff’s injections could be given	L: Well, I was taken ill so consequently respite care <u>had to be found</u> by the social services <u>very quickly</u> for Geoff because I just couldn’t look after him, so I had <u>no choice</u> in what happened really. And he went in, they found Nursing Home 2 (NH2) care centre but they did have a <u>great deal of trouble</u> finding anywhere that would give Geoff the injections  A: Yes
NH2 struggling Injections being a big issue Giving as and when was a problem It was a problem but not my problem Being too ill to intervene Hearing about it from others who were having to sort it out It being a problem	L: erm they struggled, even with NH2 initially, it was quite a big issue, the fact that his injections are <u>as and when</u> . And so that was a problem apparently, not for me because I was at that point <u>too ill to do anything about it</u> , but, you know, from the people who were having to sort it, it was a problem.  A: mm
Discovering what was happening Managing to see Geoff Staff not giving the injections	L: and erm I did discover really when I managed to get to see Geoff, in there, that they weren’t giving the injections as and

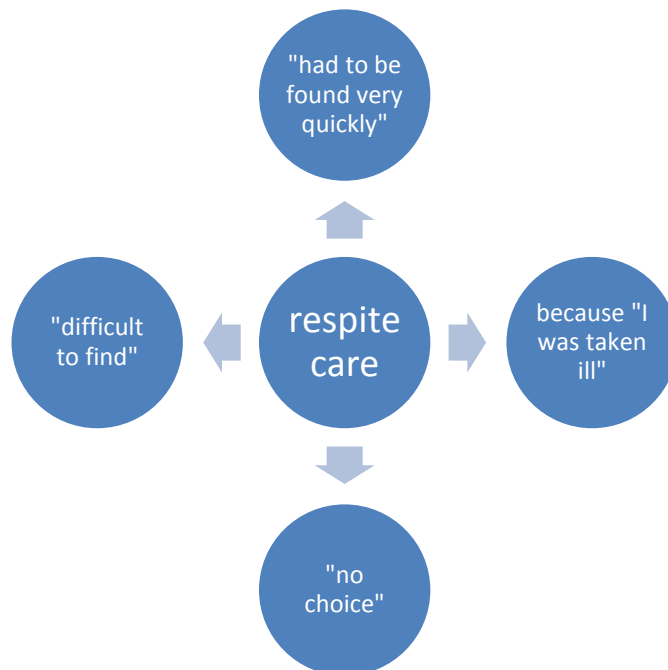
Not giving injections as she would	when, erm as <u>we could have done so..</u>  A: strange isn't it I .....
Hearing from a friend who visited NH2 not giving injections as and when Explaining to me what Geoff needs What happens if he doesn't get injections Explaining that he won't be able to move And then he will be in a panic situation	L: and even a friend went and he observed that they weren't giving them <b>as and when</b> , it always revolves a bit round the toilet, because if Geoff needs to go to the loo, he needs to be able to go to the loo, erm so if he can't move that becomes a panic situation,  A: yeah
Leading to him 'go off' Needing an injection when he 'goes off' Turning up one day Seeing Geoff not being treated properly A friend seeing this too Telling staff what they needed to do Staff not wanting to do this  The friend explaining as well	L: and really he often <b>'goes off'</b> under those circumstances, so that's when he does need an injection, yet I'd turned up one day and they were <u>absolutely dragging him</u> from the loo, erm and the same when the friend visited, and for all I'd mentioned to them that he needed an injection, <u>they were a bit loath</u> to do it at that point, and then again the friend pointed the same thing out (Lc2(iv))

Moving swiftly through the data, listening to Linda's voice on the tape recorder with the transcribed words in front of me, I underline, circle or highlight words that jump out at me and make notes and observations as I go along. Underlined words and phrases are identifying moments, circled words and phrases are ones that in some way stand out to me and highlighted words and phrases are invivo codes. I will go onto explain what these are later in this chapter. I try to make sure that my initial line by line coding is open and that it uses gerunds to emphasise process and action. I reflect that this process feels very interactive and alive and I hope that my coding captures the reality of Linda's world as she is living it. The following are key points from my analysis of this extract

- **Setting the scene**

In the first paragraph, we are immediately drawn into a problematic situation. “Well, I was taken ill so consequently, respite care had to be found ....for Geoff.” I circle respite care – what does it mean here? Already, it is clear that this is an intervention that has to meet the needs of 2 people - Linda is ill so Geoff will need respite care. This is the primary focus of my study and I look for meaning in this taken for granted term and note the way it is used in this context. Fig 5.4 below shows the meaning of respite care within the context of this particular situation in a diagrammatic form:

Fig 5.4 Meaning of respite care (emergency)



The diagram presents a problematic picture where respite care is something that has to be found because Linda was ill. There was no choice and it was difficult to find. Linda is ill but the issue of respite care for Geoff and the difficulties surrounding it are the focus of the extract. From listening to the way Linda spoke about this and staying close to the data, I think this reflects the way Linda must have felt at the time. She was so ill, she couldn't think past the fact that she just wasn't able to look after Geoff. It emphasises Geoff's dependence on her, and that she had no choice or control over what would happen next. There's a sense of urgency. I circle 'respite care' which 'had to be found' 'very quickly'. There was 'no choice' and social services had a 'great deal of trouble' finding somewhere that would give Geoff his injections. The line by line coding brings out the urgency of the situation but stops us from forcing the emerging themes too quickly. As described earlier, diagrams are considered to be central to Grounded Theory work

(Lempert, 2007) and the form of this diagram as shown in Fig 5.4 above became a style that I used frequently in the coding process. As I was making notes, I found myself using the simple concept map style circles to help me capture the emerging themes. On reflecting on how I was using this simple style of diagram, I decided that I would continue to use it for the following reasons:

- Simplicity
- Clarity
- The diagrams put the subject at the centre of the process
- The diagrams could be compared to other diagrams in keeping with the constant comparative method

An example of the use of the diagrams to make visual comparisons can be seen later on in this chapter, section 5.6, Fig 5.6.

- **A note on ‘injections’**

In trying to capture a slice of Linda’s world, I had to understand about the injections that she mentions several times in the extract. The injections which Geoff has to have cause social services “a great deal of trouble”, they had to be given “as and when” which is “quite a big issue” and a “problem”. NH2 “weren’t giving the injections” “as and when” which means Geoff can’t move at times. If Geoff doesn’t have the injections, he “goes off” which has serious implications for him. The reason these words and phrases are highlighted is because I considered them to be ‘in vivo’ codes (Charmaz, 2006) I will explain these shortly. In the first instance, we simply need to know what the injections are. I made a note at the time:

Note on 'injections'. These are apomorphine injections. Used in the management of Parkinson's Disease, apomorphine is a dopamine agonist which reduces the amount of time the person spends in an 'off state'. This is when the drug levodopa becomes less effective and its positive effects wear off more quickly. As the disease progresses, the person is likely to spend more time in an 'off' state as opposed to an 'on' state. This means that the person is more likely to experience difficult symptoms to the extent of not being able to move at all at times. This is sometimes referred to as 'freezing' This can be very frightening. An injection of apomorphine given when the person feels they need it can relieve these symptoms and allow the person to carry on moving more freely.

Once we know what the injection is, our understanding of Linda's world is enhanced. How worried she must have been about Geoff knowing that without access to his injections he would be suffering these frightening experiences without her there to look after him. We understand how important it is and we are left at a loss as to understand why it is difficult to find somewhere that can give the injections as they are prescribed and why it is so problematic in a nursing home setting.

- **In vivo codes**

By looking for meaning in the in vivo codes, we may find some clues as to why the injection issue is so problematic. Charmaz (2006) describes in vivo codes as participant's special terms. "*In vivo* codes that condense meanings consist of widely used terms that participants assume everyone shares" (Charmaz, 2006 pg 55). As part of the process of initial coding, these require unpacking so that meaning can be found and it is in keeping with the principle of seeing the world through the participant's eyes. In the extract in Fig 5. 3, I identified "as and when" and "goes off" as in vivo codes.

"As and when" is a phrase that refers to how Geoff's injections are required to be given. The terms as and when means that the injections should be given 'as and when' they are needed. "Goes off" refers to Geoff being in what is known as an 'off state' as described in the note about injections above. Through Geoff's illness, Linda has become totally familiar with what could be called a kind of healthcare

shorthand to the extent that it has become part of her everyday language. Analysing this language sparked off several ideas in my mind and in unpacking the in vivo codes, I was opening the words up to theoretical possibilities which I could analyse further. First, that through caring for Geoff and learning about his illness, Linda has developed some 'professional' expertise. She knows the terms, she knows what they mean and most importantly, she knows what they mean in the context of her husband's condition. This is an example of being open to the theoretical possibilities in the words. From the initial coding of this interview, I had established that the giving of Geoff's injections was problematic. It was problematic to find somewhere that would give them. Presumably, NH2 must have agreed they could give them but as we follow the extract, we discover that they weren't giving the injections as Linda would have done. The use of in vivo codes emphasises that Linda has knowledge about this that the staff who are taking over his care do not. This knowledge is also shared by their friends. There is evidence that they try and help staff to understand what Geoff needs as well but the final paragraph from this extract shows us that for whatever reason, staff appear not to be prepared to be advised by the people that know Geoff best and as a result, Geoff does not have his needs met and he experiences poor care:

Leading him to 'go off' Needing an injection when he 'goes off' Turning up one day Seeing Geoff not being treated properly A friend seeing this too Telling staff what they needed to do Staff not wanting to do this  The friend explaining as well	L: and really he often 'goes off' under those circumstances, so that's when he does need an injection, yet I'd turned up one day and they were <u>absolutely dragging him</u> from the loo, erm and the same when the friend visited, and for all I'd mentioned to them that he needed an injection, <u>they were a bit loath</u> to do it at that point, and then again the friend pointed the same thing out (Lc2(iv))
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The question of 'who has the knowledge?' which I believe is central to this problem was a recurring theme in other interviews and later became the subject of a memo.

- **Identifying moments**

The line by line coding in this section draws us in to the 'one thing leading to another' scenario that really captures this sense of Linda knowing that Geoff 'goes off' if he doesn't have his injections as they need to be given and along with his friends, having to witness the consequences of this. I underlined "absolutely dragging him" because it stood out to me. I reflected afterwards that the reason it had stood out to me was because it was a phrase that captured a number of feelings within it. As well as Linda seeing the consequences of not being listened to, the language makes clear that her perception is that Geoff is experiencing poor care – how can 'dragging' be anything to do with care or nurture? Within this, I felt there was a sense of helplessness and within that again, a sense of Geoff's vulnerability. Linda goes on to say that she had mentioned to staff again that Geoff needed an injection. She uses the phrase "they were a bit loathe to do it" which adds to that sense of not being listened to and it definitely suggests a disparity between her distress, Geoff's suffering and their apparent inability to respond. Charmaz (2006) explains how she developed the code of 'identifying moment' from some early observations in her work with chronically ill people. She gives an example from her field notes about how she felt when interviewing a married couple who both had chronic illnesses. She is asking the husband about his work as a college professor and whether he has kept up any professional work since his retirement. He is explaining that he can no longer do the extension courses he

used to do because of the college's lack of money. His wife cuts in at this point to say how successful her husband used to be but that he can't do these courses now because of his speech problems. Her husband then adds, in Charmaz' words, "slowly and painfully" that "the schools don't have any money....I can't speak very well" (Charmaz, 2006 pg 59). Charmaz codes this an identifying moment – as she describes it – this brief interaction had "imparted a shocking image of whom the ill person had become". She was then able to code other brief interactions in a similar way though not always negative. I felt this with the last paragraph of the extract and most particularly the phrases "absolutely dragging him" and "they were a bit loathe to do it". As with Charmaz's extract, the phrases impart a "shocking image" (Charmaz, 2006 pg 59) – so brief, yet so full. I too went on to recognise further identifying moments in my interviews with participants. I found this idea of identifying moments "resonating with many experiences" (Charmaz, 2006 pg 60) to be very helpful in terms of developing concepts that captured the complexity and depth of the participants' experience of respite care within their particular reality. Other examples of identifying moments include the words of a carer whose spouse would not go anywhere else for respite care other than the hospice where the availability of respite care is very limited. They have tried other places....

Dick: ..... "but the place has to be right, the people have to be right, we've tried it and it didn't work. It didn't work at all and it was an absolute nightmare, so much so that she said I won't be going again but it's come to the situation now where I need, desperately need some quality time. I've served my sentence up to now, 10 years, and I need I mean, I'm not stupid enough to say that the situation will ever go away because it won't and it will get worse, that I do know, but I've come to the stage where I need this situation taken off my hands, if only for a week so that I can just go away. Oh you can't forget, they still ring and all that business erm..... And I don't see a solution, I don't see any solution at all; there is no light at the end of my tunnel, I can tell you that now." (Dc1(viii) Lines 250-265)

As in the previous example, these words portray a shocking image of how life is for this carer. The hardly stopping for breath nature of the sentences that are filled with despair culminating in the stark statement that “there is no light at the end of my tunnel”. In a few lines, the carer has given us a view of his world from where he is and more than anything, it strikes us how important respite care is to him. So for all there might be a lack of research to support its efficacy (Wolkowski et al, 2010), one cannot underestimate its importance as shown in this extract. If there was going to be any light at the end of the tunnel, it was going to be in the form of acceptable respite care. But again, such a short extract, but so full. In the same paragraph that says how important it is to him, he also identifies another recurring theme which is to be found in the line “oh you can’t forget, they still ring and all that business”. I initially coded this as “not being able to forget” and “they (meaning people looking after the cared for person) will still be ringing”. It really struck me that although respite care is supposed to provide a break from caring for somebody, this carer is taking it for granted that whoever does look after his wife will still ring him with, I’m presuming, any queries they have about his wife’s care and he won’t be able “to forget”. So the extract is full of tensions that I feel are part of why there is a lack of research to support the efficacy of respite care. So much about it is complex. How acceptable it is relies on it being “right” for the carer and the cared for person and implicit in this is that the individual and different needs of two people require to be met. The needs of the carer are to be able to have a rest from their caring role. Even at the most basic level of understanding of respite care, there should be an expectation that if nothing else, it will be a rest for the carer from their caring duties. But in this sentence, the carer suggests that he takes it for granted that while he is having a rest, he will be called about his wife’s care. Again the question of knowledge. Who has the knowledge and what sort of

knowledge is required for organisations to provide the sort of respite care that is 'right' for the carer and the cared for person? In this extract, the identifying moment captures the carer's sense of despair as well as the tensions within the concept of respite care.

## **5.6 Focussed coding: developing categories**

As I analysed the interviews that followed, themes started to emerge that I could compare with themes from previous interviews. In order to be able to develop categories, I had to progress from the initial coding to what Charmaz (2006) describes as focussed coding. This allows us to categorise large amounts of data which we can then compare with other data. Along with memo writing, this process of categorising and constantly comparing leads to the development of concepts that will go onto form the foundations of our Grounded Theory. Fig 5.5 below shows how by moving from line by line coding to focussed coding, broader themes can be drawn out and the more theoretical categories can be compared. The continued emphasis on actions and processes rather than individuals allows concepts to emerge.

Fig 5. 5 Focussed coding

Focussed coding	Line by line coding	Transcript
<p>Respite care needed urgently</p> <p>Social Services taking over</p> <p>Losing choice</p> <p>Being parted</p> <p>Caring for Geoff is a problem</p>	<p>Telling the story. Being taken ill</p> <p>Respite care having to be found for Geoff</p> <p>Social services having to find this quickly</p> <p>Not being able to look after Geoff</p> <p>Not having choice/control</p> <p>Geoff went to NH2</p> <p>Social Services having trouble finding somewhere where Geoff's injections could be given</p>	<p>L: Well, I was <u>taken</u> ill so consequently <u>respite</u> care <u>had to be found</u> by the social services <u>very quickly</u> for Geoff because I just couldn't look after him, so I had <u>no choice</u> in what happened really. And he went in, they found Nursing Home 2 (NH2) care centre but they did have a <u>great deal of trouble</u> finding anywhere that would give Geoff the injections,</p> <p>A: Yes</p>
<p>Losing control</p> <p>Being too ill to intervene</p>	<p>NH2 struggling</p> <p>Injections being a big issue</p> <p>Giving as and when was a problem</p> <p>It was a problem but not my problem</p> <p>Being too ill to intervene</p> <p>Hearing about it from others who were having to sort it out</p> <p>It being a problem</p>	<p>L: erm they struggled, even with NH2 initially, it was quite a big issue, the fact that his injections are as and when. And so that was a problem apparently, not for me because I was at that point <u>too ill to do anything about it</u>, but, you know, from the people who were having to sort it, it was a problem.</p> <p>A: mm</p>
<p>Losing role</p> <p>Losing control</p>	<p>Discovering what was happening</p> <p>Managing to see Geoff</p> <p>Staff not giving the injections</p> <p>Not giving injections as she would</p>	<p>L: and erm I did discover really when I managed to get to see Geoff, in there, that they weren't giving the injections <u>as and when</u>, erm as <u>we could have done so...</u></p> <p>A: strange isn't it I ....</p>
<p>Friends helping</p> <p>Knowing what Geoff needs</p>	<p>Hearing from a friend who visited</p> <p>NH2 not giving injections as and when</p> <p>Explaining to me what Geoff needs</p>	<p>L: and even a friend went and he observed that they weren't giving them <u>as and when</u>, it always revolves a bit round the toilet, because if Geoff needs to go to the loo, he needs to be able to go to the loo, erm so if he</p>

Being helpless when Geoff is at risk	What happens if he doesn't get injections Explaining that he won't be able to move And then he will be in a panic situation	can't move that becomes a panic situation,  A: yeah
Witnessing poor care  Not being listened to  Friends helping	Leading to him 'going off'  Needing an injection when he 'goes off' Turning up one day Seeing Geoff not being treated properly  A friend seeing this too Telling staff what they needed to do Staff not wanting to do this  The friend explaining as well	L: and really he often 'goes off' under those circumstances, so that's when he does need an injection, yet I'd turned up one day and they were <u>absolutely dragging him</u> from the loo, erm and the same when the friend visited, and for all I'd mentioned to them that he needed an injection, <u>they were a bit loath</u> to do it at that point, and then again the friend pointed the same thing out (Lc2(iv))

Through the process of focussed coding, categories emerged that were common in carers descriptions of the type of respite care that they had no choice about having i.e. when they were ill.

- Losing control
- Losing choice
- Being parted
- Knowing what the cared for person needs
- Not being listened to
- Witnessing poor care
- Not being able to access hospice care

For example in remembering the need for this sort of respite care, Mary still becomes upset

“Mary: And it was if you do not get your husband into respite, you cannot have this operation, and it was an operation often that I needed, you know, desperately. And that’s how it happened really, because necessity, you know. I had to get him away somehow, somewhere and therefore I often had to let other people choose.”

Anna: yeah. And how was that? How was that having to... that whole feeling that Ron had to go away somewhere, was that something that you both accepted or was that difficult?

Mary: Sometimes, Ron had to be talked into it by someone else, by say social services or some medical person, doctor or anything ‘because you must go you must help Ron’. This put him, it was not very good that, it was almost like emotional blackmail. Which was not a nice phrase to use really but... and that worried me, because I sometimes was given 4 places to choose from erm I did about 5 one afternoon I think, exhausted me, it upset Ron going round looking at the places and I am afraid most of them I had to turn down. And I’m not, I wasn’t expecting everything inlaid with gold, but when it came to a broken bedroom window that you could get your head through, or sharing a room with someone with Alzheimer’s, I felt that Ron would have been, erm a hazard to them because of his walking, so it was very stressful, choosing was stressful (becomes upset).” (Mc1(v) lines 59-79)

And for another carer when she had had no choice but to let her husband have respite care in a particular nursing home setting

Anita: “And I knew as soon as I walked in I thought ooh, I can’t leave him here; I can’t leave him here, but I had to” (becoming upset) (Ac1(vi) lines 515-516)

Clearly again, the underlined phrases leap out as capturing not having choice in these situations or if there is any choice, it is stressful, and the associated distress is evident. In addition, the theme of losing her role as the protector of her husband in “I can’t leave him here, but I had to” emerges and in turn the vulnerability of her husband is also evident.

In keeping with constant comparison, it was important to compare this view with that of the service users I interviewed. In asking them about this, I was struck by how through their illnesses, they have to accept to a greater or lesser extent that through being dependent on their carer, they have to accept a loss of choice. The interviews demonstrated that differing views were held varying from being stoic and accepting to being unhappy and reluctantly accepting. If respite care was needed urgently, it generally meant that a hospice admission was not possible because of limited availability. In keeping with the literature, the hospice was both the carers and cared for person's preferred place for respite care (National Audit Office, 2008) to a greater or lesser extent. For example, in this extract, I asked Nora about her experience of The Oaks Hospice and following on from that, what if she had to go somewhere else in an emergency:

“Anna: So it's quite a positive experience for you?

Nora: Oh absolutely, number 1. And I mean as for these other places, we've been to look at the Bay [residential care home] because you can't go in The Oaks all the time, but I say I want to be in The Oaks all the time I don't want to go anywhere else.....(Np1(viii) lines 101-105).....

Anna: If you couldn't go to The Oaks, you said you're concerned about some of the other places, but if you really didn't have an alternative would you still go even if you weren't that keen on somewhere?

Nora: No

Anna: No?

Nora: No that's a no no (said firmly). If I couldn't go to The Oaks, and I had to go somewhere else, I wouldn't think about it. I would well maybe I'd have to go, I would have to go but it wouldn't be my choice, and really I mean coz Dick says 'I aren't pushing you into anywhere' he said but it's up to you if you want to go you go if you don't you don't." (Np1(viii) lines 288-299)

In this short extract, the actions and processes are clear. Line by line coding reveals a process of Nora trying to exert control on her situation. Telling us where



she wants to be, knowing that she can't be there all the time, but still wanting to be there and making it clear she does not want to have to go anywhere else. She is saying no to going anywhere else for respite care at least 5 times! But then, in the same sentence, she realises that if there wasn't an alternative, she would find herself having to go which, she makes clear, wouldn't be her choice. But there's also a sense of vulnerability in this. Nora initially tries to show that she has some control over her situation by asserting that she will only go where she wants to go for respite care. We can presume that this assertion is based on past experience of where she feels safe and cared for and where she doesn't. In spite of her initial assertions, she has to accept that if there wasn't an alternative and she had to go somewhere, then she would have to go wherever that may be – the decision would be out of her hands. As Mary remembers in the extract above, sometimes her husband had to have respite care and sometimes, because she was not able to, she often "had to let other people choose" where he went. Focussed coding allows the categories of 'losing control' and 'losing choice' to emerge and be compared with other data. In comparing these categories, the category of 'being vulnerable' emerges which can also be compared with other data.

Geoff had found himself in the position of not having a choice when he had to go to a nursing home when Linda became ill.

"Geoff: but the respite care that we were looking for at NH2 couldn't be offered really. Had this terrible mix up between what could take place for things like injections, and who would administer it and the staff and volunteers didn't impress me much at all.

Anna: Right, why didn't they impress you?

Geoff: I don't know really, just got the impression that they were scurrying away..."(Gp2(iii) lines 57-63)

As Geoff had had to go to hospital from there as an emergency, I ask him about that experience,

“ Yes, because they couldn’t cope. Seemed senseless sending me there in the first place, if I was going to require immediate cover from the hospital” (Gp2(iii) lines 86-88)

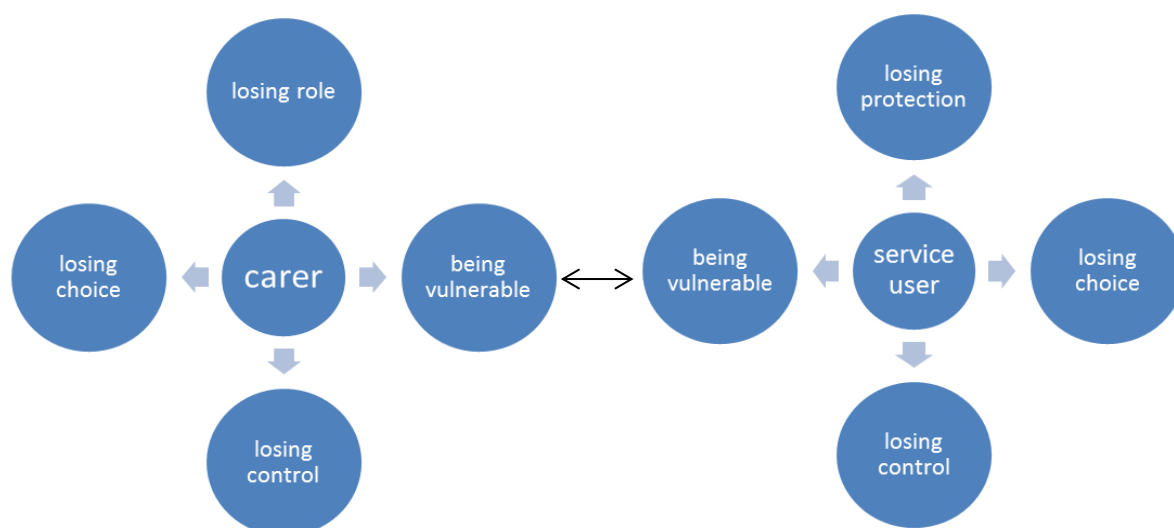
Apart from that interesting phrase which I will return to later about why he was not impressed with the staff and volunteers at the nursing home – that they were “scurrying away” - from this extract, we can see that Geoff had no choice in where he has to go for respite care. But more than lack of choice, the words “sending me there” suggest to me that Geoff had no say in the matter whatsoever. He is sent, I would say from his description, almost like a parcel, to a place that for him, didn’t know how to look after him. He is unable to see the sense in this and again, as well as the theme of vulnerability emerging from the data for me, there is an overarching theme that continues to emerge as the data is analysed: respite care is not straightforward. As I wrote in my field notes after I had completed an interview with a carer and a service user:

“What is it about respite care that makes people think anyone can do it? These are people with really complex needs but because they’re cared for at home by the family, there’s a feeling that their care comes into the bracket of social care rather than health care and they can be more or less put anywhere. I have fallen into this trap before myself. Why do people who are cared for at home need to be cared for in a ‘qualified environment’? But maybe it isn’t about qualification, maybe it’s about knowing the patient and/or having a knowledge of a particular condition that the patient suffers from – this has come up. What I’m completely clear about is that just because someone is cared for at home doesn’t mean to say that they do not have complex needs. This is why they usually end up having interventions when they come into a hospice setting. This is maybe why people prefer a hospice setting?”

Through the coding process as shown through the examples given, categories emerge that are common to carers and carers, carers and service users, and

service users and service users. Concerning emergency respite care, Fig 5.6 below shows the categories that are common to both service user and carer.

Fig 5.6 'Being vulnerable'



As explained earlier, this diagram is an example of how using the simple concept map style diagram allows visual comparisons to be made. In this case, emerging categories that are common to both service users and carers in the experience of emergency respite care can clearly be seen and compared. Although both service user and carer are found to be losing choice and control, this manifests itself differently in the carer and the cared for in the losing of role for the carer and as a result of that, loss of protection for the cared for. These categories come together in the emerging of the concept of 'being vulnerable' shown in the diagram as a double ended arrow going between the 'being vulnerable' circles.

## 5.7 Identifying themes: a second layer

The sections above give examples of the Grounded Theory process I followed in order to start to develop categories and concepts from interview data. But as Fig 5.1 (The process of analysis: an application) at the beginning of this chapter

shows, this was not a linear process and this section shows how I found adding another layer of analysis before I went onto more focussed coding useful. Following line by line coding of the first 3 interviews with a service user and their carer, I felt that before I could develop categories, I needed to include another level of analysis. This was probably due to my inexperience but I felt I needed to flesh out the emerging themes in a way that would provide me with some direction for the next interviews and also help me to be sensitive to similar themes and new themes in future interviews. Although still quite descriptive, I felt that this would help to capture the richness of the data at the same time as providing a bridge for me to be able to develop a more theoretical interpretation of it. I was also aware that my study needed to have two outcomes. One was to produce a theory but the other was to show how the development of the theory was influencing my practice. As such, there felt like there was a need to capture – at quite a descriptive level – what elements of service users and carers experience of respite care at the hospice were helpful and which were not so that their views could start to influence the way they received services from the hospice at least.

So the process for this second layer was to return to the line by line coding and to cluster phrases, extracts, identifying moments and any in vivo codes under headings. For an example of this work see Fig. 5.7 below:

Fig 5. 7 A second layer of coding

<p><b>Carer interview 1</b></p> <p>Respite care (day care) at hospice as mutually beneficial?</p>	<p>“which has been for me a huge relief because I’m basically totally trapped with him” (129-130)</p> <p>“He makes new friends” (147)</p> <p>“my respite day” (145)</p>
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<p><b>Carer interview 2</b></p> <p>Ideal type of respite care?</p> <p><u>Identifying moment</u></p>	<p>“Oh it’s fantastic, from my point of view it gives me that little bit of freedom when I know he’s looked after well, I know he’s happy, I know that at least there are other people that he can chat to so it’s stimulating for him to see different people. So really we are both benefitting.” (279-283)</p> <p>“I would like somebody here permanently looking after him <i>laughs</i> I would do it alongside him, that would be ideal but just a pipe dream of course” (172-174)</p> <p>“I could enjoy his company” (178)</p> <p>“It would be heaven wouldn’t it?” (396)</p> <p>“he’d still be trapped in the house” (402)</p> <p>“day therapy beneficial whatever”(399)</p> <p>“There’s no structure in his life” (341)</p> <p>Day care brings structure” (343)</p> <p>““he gets to meet people, but I don’t” (409)</p>
<p>Feelings associated with planned in patient respite care at hospice</p> <p>(1 week)</p>	<p>“It definitely helps” (214)</p> <p>“I feel slightly carefree”(219)</p> <p>“Well I mean I suppose, I feel sorry for him because he’s away from the home, and he’s sort of forced into that position”(227-229)</p> <p>“Which is sad” (231)</p>
<p><u>Identifying moment</u></p>	<p><u>“I knew I was at the point where I wanted him home, because I was feeling sorry for him. I think when he first went in, I was feeling sorry for me” (322-324)</u></p> <p>“it does really give you a break but can’t necessarily go anywhere” (54)</p>

	<p>“everyone in couples” (57)</p> <p>Planning is difficult” (58)</p> <p>Need to catch up at home” (59)</p> <p>“Life can be a bit more normal”(65)</p>
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Similarly, with the first service user interview as shown below:



<p><b>Service user interview 2</b></p> <p>Feelings associated with planned in patient respite care at hospice (1 week)</p> <p>Ideal type of support?</p>	<p>"When I've had enough of her <i>laughs</i>.... And <i>giggling</i> when she's had enough of me! (166-168)</p> <p>" .... Erm I don't cook, I probably wouldn't starve but if I had to look after myself, I would find it extremely difficult, if not nigh on impossible" (180-182)</p> <p>".What I think - possibly help around the house" (191)</p> <p>then that would be quite ideal wouldn't it?" (195)</p>
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At a descriptive level some of the themes that emerged from this analysis were concerning basic social processes like having a purpose. Fig 5.7 clearly shows that the service user gains much from having respite day care at the hospice. In terms of supporting his relationship with his wife, a theme emerges about needing your own space but there's also an emphasis on developing relationships with others at day therapy – "a few people together – we have a sort of common aim and we go for it". Themes also emerge about having choice – "you can sit where you want, do what you want". These themes are brought together in the diagram, Fig 5.8, below:



Fig 5. 8 hospice respite day care (service user)



The carer speaks of hospice day care in an equally positive way in the extracts in Fig 5.7 above. Themes emerge such as being able to have a rest and “a little bit of freedom” – “it’s been a huge relief”. It’s a valued day – “my respite day”. Not surprisingly, the reasons the carer can enjoy it are because she knows her husband is well looked after – “I know he is happy”. These themes are brought together in the diagram, Fig.5.9, below:

Fig 5. 9 hospice respite day care (carer)



As the carer puts it, her view is that both she and her husband are benefitting from respite day care and within that there is a sense of sustaining the relationship and developing what I coded as 'being resilient'.

As ever, the data is rich and for the carer and service user, there are tensions within the positive statements expressed. For the service user, these are related to building relationships. While there is a gain here, there is also potential for loss in that some of the people you build relationships with will die. He describes it as almost coming as a surprise to begin with – “people started disappearing”. It is as far as Geoff is concerned “inevitable at a hospice”. I coded this as ‘coping with loss’. For another service user, this was also something she had had to come to terms with in attending day therapy and going for respite care in a care home

specifically for people with Multiple Sclerosis. She explained how staff handled this sensitively. She gave an example of it by telling me about when she arrived there for a period of respite care, she might be looking for someone she hadn't seen for a while. She said that staff would then say that that person had died – “and that's the nice way they put it....and nobody has to ask has so-and-so died?”. For her, this was more difficult to cope with when having respite care on the inpatient unit of the hospice where people were as she put it, more poorly than her – “nearer death”. When I asked her about how that made her feel, she said it had “a sobering effect” and described it as making her feel almost “lonely”. Although she said that wasn't quite the word she wanted, she ended by saying that you had to be “respectful of other people that are in there”.

For Linda, the drawbacks are also to do with building relationships. When I asked her about what her ideal kind of respite care would be, Linda said that it would be to have Geoff at home with someone permanently looking after him – “I would be able to enjoy his company”. But she goes on to say that that might not be so good for Geoff and that day therapy is beneficial for him in its own right. If he were looked after at home, he would be “trapped in the house” and wouldn't have the benefits of day therapy which brings “structure to his life” and relationships – and here lies the complexity in the form of the identifying moment – “He gets to meet people, but I don't.” I coded this as ‘feeling left out’ and this was a theme that other carers identified with. This reinforced to me how respite care has to be about two people if the needs of both are going to be met and for the service user, we should not underestimate the impact of an environment where losing friends is inevitable.

## **5.8 Discussing respite care with staff: the practice issues.**

Although the process of analysis showed hospice respite care was not without its drawbacks, it was preferable to other settings and surprisingly for me, themes that emerged from the data about hospice day care particularly showed that there was much that was mutually beneficial for both carers and service users. The problem was, in the context of the examples I have given, in patient respite care was rarely able to be accessed in an emergency situation because of its limited availability.

This became a practice issue that I discussed with colleagues and as a result, in 2009, we started a process of reflecting on the use of our 2 respite beds. The way these multi-disciplinary meetings came about was interesting in itself. At this stage in my data collection, my primary concern from a practice perspective was that our current use of respite beds prevented us from being able to respond flexibly should an emergency need for respite care arise. However, the discussion proved to be much more than I expected with many views being expressed and a lack of clarity about the purpose of respite care emerging in a way that was reminiscent of the findings of Payne et al (2004) in their "survey of the perspectives of specialist palliative care providers in the UK of inpatient respite". The discussion reinforced all my feelings about why I had started the research in the first place. On the surface, respite care was something we provided successfully in the sense that the 2 beds were always booked for over a year in advance. The beds were continually filled, service users and carers were appreciative and there was a seemingly endless waiting list but this had led to a stagnation of thinking about what we were providing. It had become a taken for granted aspect of our care provision that just didn't seem to be talked about in a way that reminded me of the lack of research about respite care in the literature. Respite care patients didn't go through the same referral system as other patients who were admitted for pain and

symptom control or terminal care and service users and carers had little choice or control about when they could have a period of respite care. What tended to happen was that a service user would be referred and they would then go on the waiting list with a week's break maybe being booked for some time often many months ahead. In the meantime, if a gap arose, they would be contacted by the hospice to see if they wanted to take up the offer of inpatient respite care. The nature of this would mean that little notice was given and therefore although usually very gratefully received, there would be little time for the carer to plan to take a holiday for example. Sometime carers refused this because they just didn't have the time to get themselves organised or they had nothing planned. This was mentioned in my data collection. So although valued by the service users and carers that were able to access inpatient respite care at the hospice however infrequently, the way we were delivering this care felt unsatisfactory and inequitable. From my notes at the time:

"It dawned on me that service users and carers are so appreciative because there is simply nothing else. We may be providing a high quality service for those lucky enough to get it but it is neither accessible nor responsive".

So beneath the superficial general satisfaction with what we were providing, it was clear that staff had many misgivings. It felt like the system was clogged up primarily because of lack of resources but also because of a lack of clarity about the purpose of what we were providing. I genuinely think we were trying to do our best with the resources we had but as the system was clogged up, so was our thinking.

My data collection up to this point had reinforced the need to take a fresh approach and it felt like it gave colleagues permission to talk about an area of our service provision that in some way was not seen as important as everything else we did. What was interesting was how much staff welcomed the opportunity to talk about inpatient respite care, share their views and change the way we provided it. During the discussion many interesting and insightful observations were made and as I reflected on this meeting, I was reminded of how, in doing Grounded Theory, data is collected not only from the participants, but from many other sources (Charmaz, 2006).

As a starting point, I proposed using the definition of respite care as used by Payne et al in their “survey of the perspectives of specialist palliative care providers in the UK of inpatient respite”:

“occasional or intermittent temporary relief from the perceived responsibilities for the well being and safety of a person with life-threatening illness where the primary beneficiary is a carer” (Payne et al, 2004 pg 695).

The following points that were raised all reinforce the complex issues beneath the apparently straightforward provision of respite care:

- Service users and carers appreciate hospice care.
- Who should be the primary beneficiary? Is it the carer?
- If it is the carer, why do service users have interventions when they are inpatients?
- How does one define need in the context of respite care? If priority is given to service users who are admitted to the hospice on the basis of clinical need, how do we define a clinical need for respite care?
- It was felt by the senior nurses that some nurses on the inpatient unit sometimes didn't appreciate the need for respite care at the hospice.

Interestingly, the Family Support Team (social workers) who support carers in the community had no doubt about the need for it and felt strongly about how important respite care was for carers particularly when there was so little else available. This made me think about the different worlds that we operate in and how I had felt when I introduced myself to my first couple. I wrote in my diary:

“A very busy day as Director of Clinical Services – got changed at 4pm, changed my badge to researcher + saw my first couple! Hurrah!! However, I was late (my secretary had made them comfortable with a drink etc) + we all acknowledged I hadn’t made a good start!!.....Aware of how difficult this is for people. Easy to talk about ‘recruits’, ‘sample’. The practicalities of doing this are huge – people are ill – reliant on injections – need to see in ‘good periods’ – timing of interviews. Also their lives are extremely difficult. I felt with Linda + Geoff and Mary + Ron the sheer weight of their load – taken aback by it – how my world has become sanitized”.

There was something for me about how if you don’t go into those worlds, they can become invisible to you. It reinforced to me how important my research was in terms of capturing the service user and carer experience of their worlds and bringing that back to my practice.

- Because of historical arrangements for respite care, sometimes the service users and carers who manage to access the service are maybe not those who need it most.
- Sometimes service users are admitted for pain and symptom control when it transpires that the real reason for them needing admission is for respite care for the carer.
- Staff reported that sometimes respite patients on the inpatient gave the impression that they felt uncomfortable about being in the hospice without having a need themselves:

“Sometimes respite patients have said to me that they when the doctor is doing his ward round in a 4 bedded room, they feel they need to think of a symptom to complain of”.

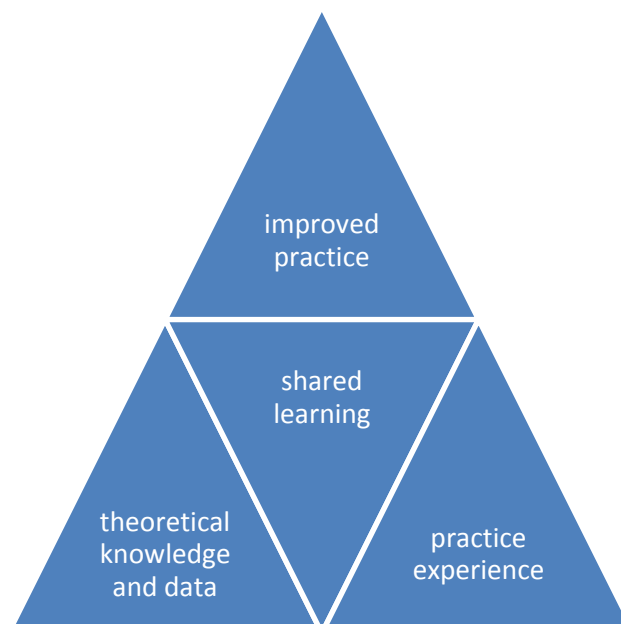
- Respite admissions take up a considerable amount of doctors’ time – they have the same admission process as any other patients. Surely if the main beneficiary is the carer, the admission could be primarily nurse led with thus freeing up the doctor’s time for patients with pain and symptom control needs or those who are being admitted for terminal care.
- The doctor’s feeling was that respite patients were complex and usually would benefit from interventions.
- That respite care is built on a deficit model in the sense that it’s only because carers receive so little support that respite care is as essential as it is.

Practical changes to practice came about as a result of these discussions and further changes have taken place since which will be reflected in later chapters. However, the important thing for me at this stage was that doing the research and sharing some insights that I had gained from my data collection at this time encouraged and enabled a more reflexive response to the issue of providing respite care in the hospice. The form it took was in keeping with the theoretical underpinnings of my study, most specifically learning through relational endeavour. By this stage in my research, I had developed some theoretical knowledge about respite care and I was also immersed in data collection. Although I had gained a level of knowledge that colleagues probably didn’t have, that didn’t mean to say that I couldn’t learn from them. So rather than these discussions being about me telling my colleagues about my advanced level of knowledge of respite care, this was about using the knowledge I had gained to



facilitate the thoughtful sharing of all of our levels of knowledge of respite care in order to develop an increased shared level of learning that would enhance our practice. This is a collaborative activity that is in keeping with a process of “relational endeavour” as described by Gergen (1999) which also promotes the integration of theory and practice. This is also in keeping with the aims of professional doctorate studies which encourage the bringing together of research, theory and practice in order to minimise anti-intellectualism in the workplace and thus reduce the theory and practice gap (Yam, 2005). The pyramid in the diagram, Fig. 5.10 below, depicts the integration of theory and practice leading to improved practice:

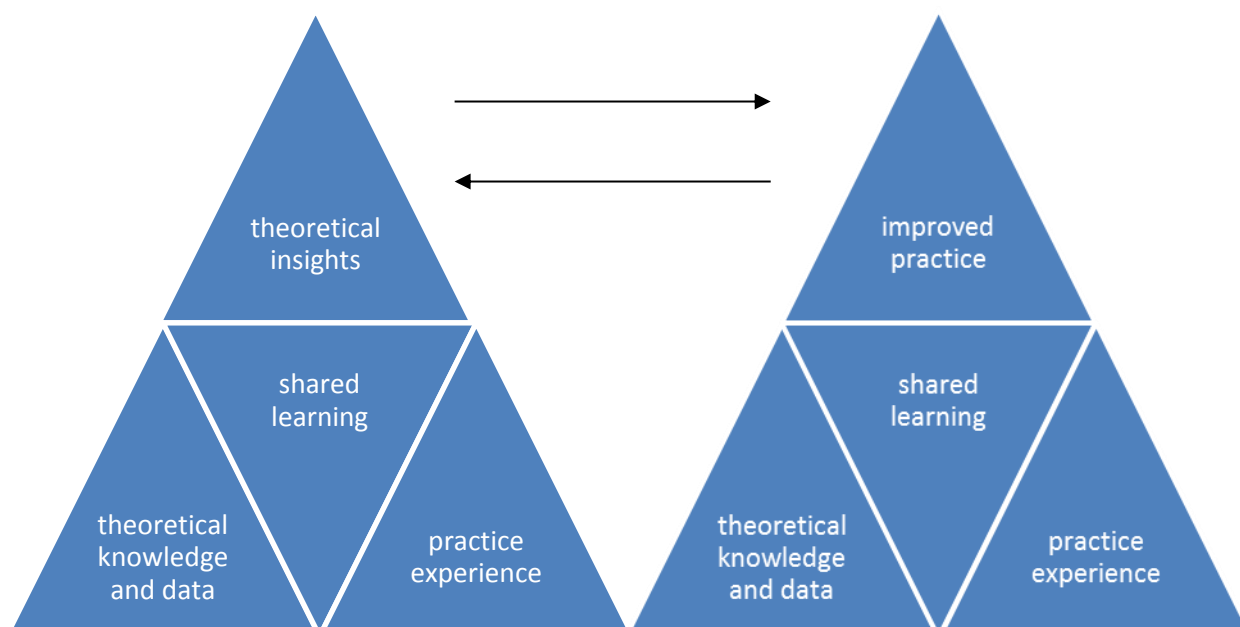
Fig. 5.10 A collaborative approach to learning



It emphasises a collaborative approach where all contributions are of equal value, coming together in shared learning which in turn leads to improved practice. It also demonstrates how a collaborative approach provides strong foundations for

progress and improvement. Fig 5.11 below shows how the shared learning was another source of data which sparked theoretical insights:

Fig 5. 11 Collaborative learning as data in Grounded Theory



The first pyramid depicts how the same collaborative process was used to develop theoretical insights in my study as in Fig 5.10 for improved practice. The two pyramids together are in the broadest sense indicative of the two outcomes of the professional doctorate, one being the development of theory and the other, the improvement of practice. It also shows how while improvements in practice do come about through the process of shared learning alone, the development of theoretical insights are likely to enhance the potential for improved practice and vice versa.

Staying close to this source of data in the same way as data for the interviews, several aspects of the discussion made an impression on me. First of all, I had enjoyed the discussion and was impressed with how interested, insightful and willing to explore the concept of respite care the staff present were. Secondly, I

reflected on the discussion and looked for themes that resonated with those that had emerged in the interviews but also, I was keen to be sensitive to any observations staff had made that may enhance my theoretical sensitivity. In other words, were there any observations made by staff that might enhance my understanding of the worlds of the participants.

In many ways, the discussion had been about trying to bring some clarity to the issue of respite care and I found that some observations particularly concerning the lack of clarity about the purpose of respite care and who the primary beneficiary should be reinforced findings in the literature (Hicks and Corcoran, 1993, Payne et al, 2004, Owen and Johnson, 2005, Satterley, 2007). What I hadn't come across before was the idea that some respite care inpatients had felt that particularly when other patients (pain and symptom control or terminal care patients) were being seen by the doctor, they had actually made up a symptom apparently because they felt a need to have to justify why they were in a hospice bed. It was almost like it was not enough to be there for respite care – not an adequate enough reason. So in a sense, the lack of clarity about the purpose of respite care sits within the service user as well. I went back to my interview data. This wasn't something I had picked up generally but one service user did say that having gone to a specialist Multiple Sclerosis home for respite care, she felt that coming to the hospice was more like being "in a hospital situation" where you're "always aware of that (people that are like nearer death) and of disturbing someone" (S+Gcp1(vii) 1183-1194). She agreed that this sometimes made her feel out of place and interestingly, when I interviewed Greta a second time as part of theoretical sampling, she spoke to me about being admitted to the hospice for pain and symptom control:

Anna:...”did you feel any different when you were in the hospice for your symptom control to when you were there for respite care?

Greta: Yeah it was as though you was well deserving of the fact I think. It feels different I suppose.” (S&Gcp2(xvi) Lines 221-225)

This made me think about whether hospices were the right place for respite care. It also brought me back to some of my initial thoughts about respite care which had led me to wanting to research it in the first place concerning the medicalization of the cared for person and the pathologizing of the relationship between the cared for person and the carer, as professionals intervene and the cared for person enters the healthcare institution. In this case, the hospice.

A key insight which I was left with was that in exploring whether respite care met the needs of palliative care service users and carers, it was important to consider the wider picture. Respite care could not be explored in isolation from the worlds that the participants were experiencing as that in itself diminished its significance. These worlds may be the external world of their living environment but also their internal world which may, for example lead them to feeling the need to make themselves more ill than they are in order to justify the care they are receiving. In order for staff to recognise the full importance of respite care, they need to see it in the context of the external and internal experiences of the service users and carers as they are living them in their worlds.

## **5.9 Literature as a source of data in the process of analysis**

In keeping with the idea that data can come from many sources (Charmaz, 2006), there were certain pieces of literature at this time that caught my eye and played their part in the theoretical interplay between all the aspects of the process of my analysis as depicted in Fig.5.1.(The process of analysis: an application) at the beginning of this chapter. My original literature review had revealed that respite care was an under researched area in palliative care and the literature I had read did not seem to capture the sort of complex themes that were emerging from my data. It was at this point that I was interested to discover literature which discussed respite care from areas other than palliative care, which focussed more on constructions of illness and disability within its provision (Clarke, 1999, Conyon, 2004). Although absent from the palliative care literature, some of the ideas behind these interesting concepts had emerged in my data collection and became part of the coding process and in turn the process of theoretical sampling.

As described above, it was clear to me that the concept of respite care could not be explored in isolation from the worlds service users and carers were occupying and experiencing. I felt increasingly that the trite way it was referred to and the lack of importance attached to how or by whom it was delivered was to some extent because of the lack of clarity about its purpose and within that, a lack of awareness or sensitivity to the lived experiences of the carer and cared for person. An area where there appears to be more clarity about the purpose of respite care is in the area of respite care for disabled children. However, I was interested to find in Conyon (2004) that despite a Department of Health Definition (1991) “primarily respite is still an ambiguous concept....with multiple classifications” (Conyon, 2004, pg17). It was refreshing to find a paper that looked under the skin of the taken for granted notion of respite care to explore its implications in terms of

“discourses relating to disability” (Conyon, 2004, pg 4) and social work practice with children and families. I was also drawn to this paper because for the first time, I had found a paper that talked about respite care in terms of social workers having a “critical self awareness of the discourse that shapes not only their own world view, but also the world view, or common sense understanding, of their clients” (Conyon, 2004, pg 5). This was the sort of depth of thinking about respite care that I had been looking for and it reinforced my view that there was more to respite care than met the eye. Primarily, the concern of the paper is about whether respite care for children is at odds with the philosophy of the 1989 Childrens Act and the principles of child centeredness. Initially, the author feels it is at odds. She presents arguments which suggest that the term ‘respite care’ is inappropriate with negative connotations underscored by perceptions of burden. That within respite care, children tend to be problematised in order that parents will be seen as in need enough to qualify for a service. And also often, because the focus of the intervention is on the needs of the parent, the needs of the child are sometimes overlooked leading to him/her having to go somewhere against his/her wishes. Interestingly, as her journey progresses through the evidence of her literature review, she concludes that in spite of this, if framed in an appropriate model, “respite care can serve as a protective factor, in terms of reducing the perceived stress of parents, and providing disabled children with the opportunity to counter the experience of disabling barriers” (Conyon, 2004 pg 49). So she concludes that respite care is less at odds with the principles of the Childrens Act than she initially thought and her position in regard to respite care shifts accordingly. It seems that although respite care doesn’t always directly benefit the disabled child, if the parents experience a high level of stress and remain unsupported, the child’s well being is more than likely to be affected. Her literature review does however

acknowledge the existence of “bad social work practice” (Conyon,2004, pg 44) in relationship to consultation with disabled children, and the monitoring and reviewing of respite placements. Within this context it also highlights the vulnerability of disabled children to abuse. I related some of the themes from Conyon’s (2004) work to themes in my interviews with participants. Respite care could have a ‘protective’ factor which could lead to positive outcomes for both the parent and child but within this, the vulnerability of the child is acknowledged once away from the protection of the parents if there is a lack of monitoring and review of respite placements. The principle is the same in respite care for service users with palliative care needs. The themes of vulnerability and protection had been evident in the data from my interviews but it struck me that there were many meanings for both within the words of both service users and carers. The concept of being vulnerable had emerged from service users and carers experience of emergency respite care. I coded this in terms of the service user ‘losing protection’, ‘choice’ and ‘control’. The carer was also losing choice and control but they were losing their role as well – the role of carer – the role of protector. When emergency respite care is needed this sense of vulnerability is heightened most particularly for the service user. But the carer is already vulnerable. For example, they are most likely to be vulnerable to illness themselves

Greta: Steve used to do everything before. He went to work and everything... he collapsed once, and after that I said no, we’re getting carers in, he didn’t like it at all

Anna : yeah

Greta: but I could see how it was affecting him, but he couldn’t. He said ‘have I complained?’ and I said ‘no’, ‘aren’t I good enough to do the job?’ I said ‘yes’ but I said ‘you’re just wearing yourself out.’ But it took a long time for him to accept carers coming in.”  
(S&Gcp1(vii)lines723-726)

Another carer, Dick, is exhausted and also distressed:

“All I do now is I am up and down the stairs 20 times a day, feeding her, washing her, looking after her and erm it becomes more and more difficult like. But I mean after 10 year but I'm getting tired now, I really am, cry for help really isn't it Anna?” (Dc1(viii)lines814-818)

The carers all said they needed respite care but issues of being vulnerable and without protection all come to the fore when the care is not as it should be as Mary explained to me when she was describing her experience of a care setting where Ron had been for respite care:

“..’now yesterday you walked to the toilet’, they would say to him, ‘why can’t you do that today?’ And they shouted at him, ‘come along, come along you can do it, you can do it.’ And I heard the shouting at one point. I went to find my husband and he was in the toilet and there was a nurse in the toilet shouting at him. So I do know it happened, it wasn’t just my husband being childish and saying ‘I don’t want to go there anymore because they shouted at me’ because these are things you have to watch.” (Mc1(v)lines254-261)

The words that I underline throughout my analysis are those that particularly stand out. For Dick above, it’s his “cry for help” in terms of his vulnerability. For Mary, it’s her husband’s vulnerability. She, like Linda earlier, has to suffer the distress of witnessing her husband being treated poorly by nurses. But what also strikes me about these lines is the sense that Mary isn’t there to protect him so the fact that they are apart emphasises that sense of vulnerability and loss of protection. The words Mary uses somehow enhance our understanding of this – “I went to find my husband” emphasises their apartness and it struck me how breaking married couples or partners up in order to address their distress is not a way of going on that would seem acceptable under normal circumstances. During difficult times, the normal societal expectation is that couples will gain comfort from their relationship – through being together rather than being apart. It is odd then that we expect couples to gain benefit from being apart especially when they are both experiencing being vulnerable and one of them is in need of protection. One of the couples I interviewed was very clear that they would prefer to have respite care



together and although they had done this in the past, there were few resources now where they could access such a service as Greta's needs had increased. Greta described how she finds it difficult to leave Steve but she does it so he can have a break. On one occasion when she was having one week's respite care at an MS home some distance away from their home, she was offered an extra week as someone had cancelled. She told me what happened:

Greta: "So I said okay, Steve said it was okay, 'you go, give you an extra rest', and the second weekend I wanted to come home, and he said 'why didn't you ring?' because I ring him every night I'm there.

Anna: Do you?

Greta: Yes, and then he puts the money on the mobile phone, it's the only time I use it (*laughing*).

Anna: Right

Greta: and I ring every night and he said to me 'why didn't you tell me? I would have brought you home' and I said 'what was the point in that?' but I would never like to go there again for 2 weeks." (S&Gcp1(vii) lines 286-297)

Once a couple is apart for respite care, carers can experience a sense of vulnerability in other ways. I have already mentioned Linda's identifying moment – "he gets to meet people, I don't" – and this sense of 'feeling left out' was felt by other carers. So, even when the respite care was helpful, this feeling and moreover a feeling of almost losing something of the partner, was quite keenly felt. Mary expresses this very poignantly in the following extract:

Mary: "There were positive things about respite, yes definitely I think.

Anna: And if I asked you, do you think it helped your relationship, did it help you sustain your relationship do you think, having respite care? It's a big question sorry,

Mary : Now that is a good question. I'm going to shatter you now.

Anna : laughs

Mary: No, not really.

Anna : mm, interesting

Mary : Because, this is very personal,

Anna: Okay

Mary: I would question myself, in my quiet moments, and think... such good reports were coming about him, how he laughed and giggled and shared with them... and I would say to myself and question myself why doesn't he always respond to me in that way?

Anna: mm

Mary: So they've done something, said something, they've got it right, have I not got everything right. Sometimes I didn't feel... it wasn't that I felt inadequate, because everybody is their own person and their own personality, has their own personality, but I thought maybe he wasn't opening up to me as much as he was opening up and sharing with other people.

Anna : mm

Mary: But that I think he probably felt it was like and almost like a counselling.

Anna : mm

Mary : certainly at The Oaks, I think that happened; where he had people he opened up to and I think benefited from it.

Anna: yes

Mary: Our relationship didn't benefit from it, but Ron as a person benefited from it.

Anna: that's really interesting

Mary : does that sound right?

Anna : yes, no it sounds...

Mary: and I think it was good for him and I felt happy about it".  
(Mc1(v) lines 407-440)

And for Anita too, accepting that Tom had a "new life and family" at the hospice was not always easy as she explains here:

Anita: he was always so grateful and 'oh thank you' and at Christmas time 'oh I must get some chocolates for so-and-so and I must do this'

Anna: yes

Anita : and I am saying what for?

Anna: yes

Anita: I said surely you don't have to write all those cards, you just write one. You're not writing them I am, I am going out to buy them and (meaning Tom would say) 'could you get so-and-so'.... and I said oh and what for you know

Anna: yeah

Anita: and (he'd say) 'they are very good'. Good I'm glad they are *laughs*, what about me? 'Well you know that I appreciate you', I said I wish you would say so sometimes

Anna: yes.

Anita: But yes and I was jealous of that sometimes.... 'you are all so special' and 'we must have a special thing for so-and-so' and you know.

Anna: So it's important, it's just as important that as the carer

Anita: appreciated

Anna: is as appreciated as the service user, or the patient. You need to be looked after as well." (Ac1(vi) lines 751-771)

And so, although happy about the care their husbands were receiving at the hospice, they were both quite independently able to acknowledge that while this was undoubtedly good for their husbands, it wasn't always good for them and indeed Mary makes it clear that it helped Ron but it didn't help their relationship.

The concept of vulnerability had already emerged from the interview data before I read the Conyon (2004) paper however, once I had read it, I felt compelled to return to my interview data to enhance my understanding of the themes of vulnerability and protection in relation to respite care. In doing this, a theme of risk

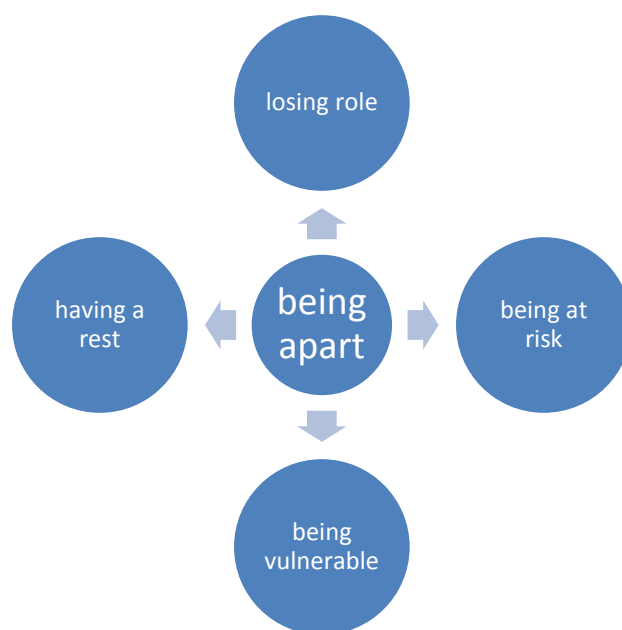
and loss also emerged. Fig 5.12 below is a diagram which shows how being apart in respite care for the service user is associated with being vulnerable, being at risk and losing protection. However, in the right setting, there can be a gain which is primarily making new relationships:

Fig. 5.12 Losses and gains for the service user in being apart



Fig 5.13 below shows a similar diagram for the carer:

Fig. 5.13 Losses and gains for the carer in being apart



This diagram suggests that in many ways, although experienced differently, carers potentially have just as many losses as the service user in being apart. However, while the service user may make the gain of building relationships in the right setting, the gain for the carer is likely to be more of a neutral experience of simply being able to have a rest.

### 5.10 Having supervision

Regular supervision with my University supervisors has been crucial throughout my study in terms of guidance, support, developing reflexivity and gaining theoretical insights during the analysis process. Following the period outlined at the beginning of this chapter in Fig.5.1 (The process of analysis: an application), I was able to reflect on the emerging themes from my interview data and plan my next steps as I moved towards theoretical sampling. I was very much aware at this

point that in spite of all the tensions about respite care that my data was revealing, there was no doubt how strongly participants felt about its importance and how much they needed it. Indeed, the reason most of the participants gave me for consenting to be part of the study was that they wanted me to know how important respite care was. Anita, for example, whose husband Tom had died, explained how his illness had changed their relationship and how she had had to devote her whole self to caring for him. She felt she had to be “in control”:

Anita: “....and it made me feel good about myself, whilst I hated the disease and I am suffering now,

Anna: mm

Anita: *(catches breath for a moment and adds in a breaking voice)* – and that’s why I feel so strongly about respite.

Anna: right

Anita: So strongly, because if I had had more, erm and carers were looked after more, I don’t think I would be suffering as much as I am now.” (Ac1(vi)lines 163-170)

She goes on to tell me some more about this:

Anita: “As far as respite was concerned, the only place that Tom felt happy was at The Oaks Hospice. And when he first started to come to The Oaks, I think we had 2 respites a year or sometimes more and they would ring up and say would you like respite and after I would say well no I am not going anywhere. How I wish now that I had taken that opportunity.

Anna: yeah

Anita: but I didn’t sort of realise at the time, but now when he did get bad and when erm I wish now there had of been more so I could have continued a life outside of Tom. Because I just became part of him,

Anna: yes

Anita: and now he has gone, I can barely function outside here, because that was my *(voice breaks)* and I don’t know who I am anymore. Oo sorry,

Anna: you're alright

Anita: And that's the difficult bit and that's why it's so important, carers should be looked after more." (Ac1(vi)lines 239-255)

Linda is still caring for her husband Geoff. She also tells me that Geoff wouldn't go anywhere else for respite care but the hospice:

"that's the thing, that's the problem and the sort of the places again, it would be a nursing home where everybody is quite frail..." (Lc(i)lines 466-468)

She goes on:

Linda: "but it's yes I think you do need a break from one another really. I think when you are in the stressful situation where and it is quite stressful when you are confined with somebody, because you do feel as though you are confined, you feel a bit trapped, and I am sure he feels just as trapped really; he's trapped by his illness and I am trapped by him having the illness I suppose.

Anna: Yes

Linda: But the illness is the thing that's trapping us both. And you feel, I obviously can try and make his surroundings reasonably comfortable, but it doesn't alter the fact that you're held back by his situation. So I mean, respite, I think most people in this situation would, I don't know you have to, I can't say that can I because everybody's different, but I think generally I get the impression that people would be glad of the rest." (Lc1(i)Lines 790-804)

As a service user, Nora is clear where she wants to go for respite care and how important it is for Dick:

Anna: "But do you think it is important for your relationship with Dick to be able to have a break?

Nora: Oh yeah

Anna: and give him a break as well

Nora: yeah it is, it is important, oh definitely I mean I can't get enough of The Oaks to be truthful, I can't get enough of The Oaks. If they came to me and said 'do you want to come every fortnight?' I would

do it, but you see it's a break for Dick and that's what I like".  
(Np1(viii)Lines 249-257)

But having said all of that the complexities underlying the need for respite care are never far away and how much long term benefit it offers is another matter. When Nora is in respite care at The Oaks, Nora tells me that Dick visits everyday:

Nora: "I mean I said to him, don't come every day Dick, you don't have to come every day, but he did come every day because he's lost, he was lost as well you know, he was lost bless him. But I think it is important for Dick to have a break. Definitely, I mean I don't care if he doesn't go away but he needs a break from me. Definitely needs a break from me.

Anna: Do you think that being able to have a break has a positive effect on your relationship, you know is it helpful?

Nora: Oh yeah, you know when I come home, he's a different person, he's quite happy again for a few weeks, and then suddenly *phurt* back down again." (Np1(viii)Lines259-271)

I have included these words from Nora here because I believe they encapsulate what I was feeling at the time about my study and the tensions within it for me. I was keenly aware of how important respite care was to my participants and it was clear that they wanted me to hear that message. But within this, I was hearing the other messages. I noted at the time:

"Dick is desperate for a break but when Nora is having respite, he visits everyday – "he's lost" Nora says. Is this something about how Anita felt with Tom – that she had no other life outside him? Does respite care help? Or is this about Dick maybe feeling 'left out' and wanting to feel more included. Nora is keen to say that the break has a positive effect on their relationship – and it does – but for how long? This is something that's so important to people but how much good does it do?"

These were the sort of issues I was taking to supervision – the debates I was having in my mind as I was progressing through my analysis. Through supervision, I was able to have discussions that helped me move my thinking onto a more theoretical level reinforcing the idea that doctoral supervision is "a two way



exchange of learning and ideas” (Lee, 2009, pg 99). I went into supervision in September 2009 with the words from the participants in the first round of my interviews very much with me. Through talking through some of the issues, my supervisors assisted me with moving the debates I was having in my mind onto a more theoretical level in terms of looking at needs and expectations. I was also wrestling with the participants’ preference for hospice care - what made it so different to other settings? Discussion led me to think about the qualities that hospice nurses have and in turn to reflect on the fundamental nature of nursing. The following is an extract from my supervision record which went on to be a memo:

A theme which is coming through is people’s perception of the quality of nursing at the hospice. Thinking in terms of current media portrayal of nursing, there is something special about the way hospice nurses nurse re humanness, caring. Have people got a different baseline now? Is anything good a surprise? Look at Virginia Henderson’s definition of nursing. Personality v qualification? Also are staff self selecting? Discussed needs/expectations/dimensions of individuality/comparisons of need – the carer/the patient and hierarchy of needs. Look at some models. Discussed Bradshaw (1972) normative, comparative, felt and expressed – concept of social need. Application of this to new patient group. How do we nurture people to express their needs. See also Monique’s work (critical public health, 2008) – “deterritorialising” processes. Also, reciprocity and imbalance – destabilising that leads to nothing.

This process of being open to emerging themes and reflecting on them and writing about them is an indication of developing theoretical sensitivity and being open to the theoretical possibilities in the data. Writing memos is also part of this process.

### 5.11 Writing memos

As explained in Chapter 3, memos are universally described as being crucial to the Grounded Theory process. “Memo writing is the pivotal intermediate step between data collection and writing drafts of papers” (Charmaz, 2006). Charmaz (2006) is infectiously enthusiastic about writing memos and Lempert (2007) is equally evangelical about their importance and power:

“For me, memo writing is the dynamic, intellectually energising process that captures ideas in synergistic engagement with one another and through naming, explicating, and synthesizing them, ultimately renders them accessible to wider audiences”. (Lempert, 2007 pg 246)

This is an opportunity, Charmaz (2006) says, to be able to engage a category and let your mind run free with it and take it to an ever higher level of abstraction. It is also an opportunity to explore and think freely without worrying about the usual constraints of academic writing – “a place for exploration and discovery” (Charmaz, 2006, pg 81). I agree with Lempert (2007) though when she says memo writing is a learned skill which takes practice if one is to truly feel the full impact of the process and the finished product. However, although a novice myself, in writing my memos, it did feel like it was an opportunity to step outside the discipline of the study for a little while and just write freely about the category and the connections that came to mind. Charmaz (2006) reassures us that producing memos relies on making them “spontaneous, not mechanical”. In order to demonstrate how I used memos in my study, I have included below, my memo on ‘not being listened to’. Later, I added the subtitle, “Who has the knowledge?” This memo was more or less written in two stages as I developed my thinking about this category into more general concerns and more abstract ideas. The aim of the diagram at the end is to show how writing the memo helped me to link my categories with developing concepts. As the reader will see, it is made up of

thoughts, notes and ideas but it always remains close to the data with examples being used throughout and themes being compared.

**Memo on 'not being listened to' (Who has the knowledge?)**

<p>Friends helping</p> <p>Knowing what Geoff needs</p> <p>Being helpless when Geoff is at risk</p>	<p>Hearing from a friend who visited</p> <p>NH2 not giving injections as and when</p> <p>Explaining to me what Geoff needs</p> <p>What happens if he doesn't get injections</p> <p>Explaining that he won't be able to move</p> <p>And then he will be in a panic situation</p>	<p>L: and even a friend went and he observed that they weren't giving them <b>as and when</b>, it always revolves a bit round the toilet, because if Geoff needs to go to the loo, he needs to be able to go to the loo, erm so if he can't move that becomes a panic situation,</p> <p>A: yeah</p>
<p>Witnessing poor care</p> <p>Not being listened to</p> <p>Friends helping</p>	<p>Leading to him 'going off'</p> <p>Needing an injection when he 'goes off'</p> <p>Turning up one day</p> <p>Seeing Geoff not being treated properly</p> <p>A friend seeing this too</p> <p>Telling staff what they needed to do</p> <p>Staff not wanting to do this</p> <p>The friend explaining as well</p>	<p>L: and really he often <b>'goes off'</b> under those circumstances, so that's when he does need an injection, yet I'd turned up one day and they were <u>absolutely dragging him</u> from the loo, erm and the same when the friend visited, and for all I'd mentioned to them that he needed an injection, <u>they were a bit loath</u> to do it at that point, and then again the friend pointed the same thing out (Lc2(iv))</p>

### First memo

This episode sparked off a lot of thoughts for me – ‘not being listened to’ had become a category. It made me think about the whole issue of the use of knowledge in the caring relationship (see **section 5.6 Focussed coding: developing categories** for analysis of this section). The use of the in vivo codes ‘goes off’ and ‘as and when’ are I think clues as indicated in analysis. The issue is that for whatever reason, staff do not seem to be prepared to listen to what Linda has to say regarding the giving of Geoff’s apomorphine injections on an ‘as and when’ necessary basis. The use of ‘goes off’ and ‘as and when’ indicate that Linda has become familiar with professional terminology. She has gained knowledge about these aspects of her husband’s care. She knows when he needs an injection and she knows what happens when he doesn’t get one. She gives the injections herself at home as do Geoff’s friends if they are sitting with him while Linda is out. We know from Linda’s interview that the injections are a problem for Geoff. Social Services day centres won’t give them and non-qualified sitters won’t. However, there should be no reason why a nursing home can’t.

There are 2 issues here – 1. this is the sort of thing that the public cannot get their heads around – Geoff’s wife and friends can give this injection. Geoff himself knows when he needs it and his wife and maybe even his friends know that too. No one has a problem with them as lay people giving the injection which is pre-prepared and safe for anyone to give without causing harm. However, social services staff are not able to give the injections. This means that a whole area of care and support is not available to Geoff and Linda. 2. In this scenario, Geoff has been placed somewhere where the injections can be given but the issue for this staff group appears to be that they can’t accept the ‘as and when’ arrangements and they won’t accept guidance from Linda about this. This sets off a spiral of deterioration in Geoff. See below re my notes:

“Evidence of influence of visitors who mentioned the need to give injections as and when. The more people mentioned it, the more staff were inclined to do as they were asked. Issue of who knows what the right thing to do is and is care based on the more people mention something, the more likely it is to happen? However, Geoff consequently ‘goes off’. Condition deteriorates. Requires hospital admission. The initial relief at finding somewhere for Geoff is replaced by the stress of knowing he is in hospital. Hospital is stressful for both. A bad experience for both.”

There is a positive here in the sense of ‘friends helping’ which is supportive, but the effect this has on the staff suggest that staff are reliant on reassurance in numbers to guide their behaviour. The more people say they should give Geoff the injections, the more at ease they seem to be with giving them. The upshot is of course that Geoff’s health deteriorates and he has to be admitted to hospital. The issue of risk emerges here. From my notes:

“How is this meeting anybody’s needs? Some needs are met. Linda illness is treated, Geoff is taken into care in order to be safe. He is literally taken out of harm’s way but actually, he is not safe from harm where he has been put. He actually suffers harm which leads to him being admitted to hospital. This is stressful to both Linda and Geoff”.

Geoff is being put at risk because staff are not listening? Staff haven’t got the knowledge?

On the subject of knowledge, the in vivo codes hold the clue. Is this knowledge that staff perceive Linda shouldn’t have? Has she encroached on health professional territory? Do these terms belong to the dominant knowledge of medicine?

Stepping out of Linda’s experience of the world as she sees it briefly, staff’s behaviour suggest that they are not at ease with the ‘as and when’ directions they presumably have for this medication. We don’t know this and it is not relevant to know in terms of capturing how Linda feels. However, from a professional point of view, there is no reason why ‘as and when’ medication cannot be given by a qualified nurse as long as the medication is prescribed correctly (NMC, 2007). It is also important to note the NMC’s ‘Standards for Medicine’s Management’ guidance on administering medication which states that “It is not

solely a mechanistic task to be performed in strict compliance with the written prescription of a medical practitioner..... It requires thought and the exercise of professional judgement.” (NMC, 2007 pg 1). However, whatever the motives of the nurses, there was a poor outcome for the patient that - if we step back into Linda’s experience of this world – appeared simply to do with them not being prepared to accept that she had a knowledge of the patient that would help them to meet his needs appropriately.

#### Later development of memo

I found the theme of the carer ‘knowing what the cared for person needs’ or more broadly, ‘carers having knowledge’ in other participant interview data. Dick talks about Nora’s rapidly changing condition and that he’s “forever doing her **blood sats** and things like that”. I would call **blood sats** an *in vivo code* as it is, as with Linda, a participant’s special term and similarly, it is again a sort of professional shorthand for oxygen saturation levels in the blood. Dick has learned how to check these and interpret them. He goes on:

“they weren’t very good at all yesterday day and night and then this morning we woke up and they were smashing. Now then, they are smashing now, but in two or three hours they might not be” (Dc1(viii)lines 208-212)

He’s also learned to manage Nora’s **“exacerbations”**. Again, an *in vivo code* referring to acute worsening of the symptoms in chronic obstructive pulmonary disease (COPD). Such exacerbations often lead to COPD patients being admitted to hospital but Dick has learned that there are self-management techniques that can help to avoid this being necessary. Interestingly, he reports that while in residential care for respite care, “she was only in a day and finished up in hospital because she had an **exacerbation** because she got panicky and what have you” (Lines 73-76). Dick is telling us that through caring for Nora, he has gained knowledge that helps to keep her at home and out of hospital. Other people who look after her may not have this knowledge and as such, Nora is more likely to be admitted to hospital which is undesirable and potentially harmful.

It struck me that if respite care is going to be provided in such a way as to at least be in keeping with how one of the service user participants described it to me: "I think you should be treated with respect, and be given the care; you don't want to be coming out of somewhere worse off than you went in" (S&Gcp1(vii)Lines 830-832), then there has to be some acknowledgement by staff who are taking over the care of the cared for person, of this special carer knowledge. From listening to the participants, it felt like often there was a tension between 'professional' and carer knowledge that was not helpful to the cared for person. Nolan (2001) discusses this in his paper on working with family carers towards a partnership approach in the context of rehabilitation. In this, he refers to the terms "local and cosmopolitan knowledge" (Nolan, 2001). Harvath et al (1994) explain how in their research with families giving care to frail older people, they use these anthropological terms to describe the different types of knowledge of the cared for person held by the family and the nurse. Local knowledge refers to the "unique information" held by the care giver about the person they are caring for that is essential to his or her care. Cosmopolitan knowledge refers to the nurses' knowledge and skills. (Harvath et al, 1994). Local knowledge in anthropological terms is knowledge that is unique to the inhabitants of a particular culture. "The term refers to the skills and understanding that the family brings to the care giving situation" (Harvath, 1994, pg 30). Cosmopolitan knowledge on the other hand is universal knowledge that is brought to a particular situation and refers to the skills and understanding that the nurse brings to the situation. The writers recommend a blending of both of these types of knowledge to secure the best outcomes for everyone involved.

This approach could provide a positive to the negative categories I have identified. The carer would feel listened to and the cared for person would be more likely to be being safe. Staff would be likely to have more knowledge because they would have learned from the carer. However, this approach takes it for granted that the paid carer, as it were, is a professional and has a universal knowledge. The experience of the participants in this

study suggests that there is often a lack of knowledge on the part of the staff who are taking over the care of the cared for person. Thus, there is likely to remain an imbalance between the local knowledge of the carer and the lack of cosmopolitan knowledge in the paid carer be they qualified or unqualified. This leaves me with a question – who is qualified to provide respite care for service users and carers with palliative care needs? Who has the knowledge?

Diagram showing how memo provided link between categories and concepts

Categories →	MEMO →	→ concepts
carer not being listened to carer and cared for being at risk staff not having knowledge	comparing themes Identifying processes developing theoretical insights possible solutions	<u>needs</u> (not being met) <u>vulnerability</u> (lack of knowledge) <u>loss</u> (loss of protection) <u>risk</u> ( to well being)

As I explained at the beginning of this section, the diagram within the memo above shows how writing the memo helped me to link my categories with developing concepts. The memo also helps us to see how things could be different from the scenarios described in which the carer is not listened to. In the family home, having the knowledge is helpful and empowering i.e., it can help to prevent hospital admission. This could be said to be being protected. Away from the family home, in the scenarios given, the normally empowering carer knowledge and expertise is rejected and therefore protection is lost and is replaced with being vulnerable. The memo helps to see how things could be different.



On reflecting about how things could be different, I was able to link this memo with another memo about the category 'preferring hospice care' which came from a theme I had discussed at supervision. There was no doubt that the preferred place for respite care was the hospice. This is in keeping with the literature (National Audit Office, 2008) and although there were drawbacks which I have already identified, there was clearly something about it that made it different to everywhere else and day therapy was particularly valued. This was a theme that ran through all the interviews and I became increasingly keen to try and capture what made the hospice so different. I look back on the interviews – the questions I asked - "...but what other sorts of things make a difference to you Nora?" and to Mary, "can you pinpoint in any way the differences?" I have included an extract from the memo that followed where I suppose I carried on having that conversation with myself. Charmaz (2006) talks about memos being vehicles for such conversations which help us to flesh out the meaning in our codes. I also found that in writing this memo, a visual element emerged. Please see below:

## **Memo on 'preferring hospice care'**

Linda: I think it is that the people seem to have time, for the patients, the carers and nurses they do seem to have time.....for everybody. And they do take their sort of suffering into consideration, they just seem to understand more. (Lc1(i) lines 513-519)

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Nora: "The reason why I like going to The Oaks is because, all the people are so caring, you get TLC and that's all what I care about is TLC. ....You know, they always come and ask you 'are you alright?' They are caring and come and give you a cuddle, you know." (Np1(viii)Lines 149-151 & 160-162)

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Mary: "...where he was allowed to do certain things when he was in day care there.....Where he was allowed to be a person, a person you see; spoken to as a person." (Mc1(v)Lines 302-305)

Mary: "I felt vibes coming from people that there was a certain amount of expertise" (Mc1(v)Lines 418-419)

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Anita: "Because it was so beautiful and the ethos there, and he was treated like a human being" (Ac1(vi)Lines293-294)

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**Staff having time**

**Staff having expertise**

**Taking suffering into consideration**

**Being more understanding**

**Being cuddled**

**Being so cared for**

**Being allowed to do things**

**Being allowed to be a person**

**Being spoken to as a person**

**Being treated like a human being**

In trying to define the fundamental qualities of hospice care that made it so preferable for service users and carers, I was taken aback by the words some of the participants used. When coding the extracts from the interviews, the words seem to fall naturally into a sort

of pattern that was balanced and almost symmetrical – almost like a poem! There was something in the way this happened that reassured me that participants weren't just saying nice things about the hospice because I was asking them and I was from the hospice – the words were far too profound and the beauty of the words came out in the coding.

The key question of course

### **why can the hospice do this and other places can't?**

I am not the first researcher to be asking this question. More generally, the question is being asked, is it only in hospices that good quality terminal care can be provided? How does it differ, if at all from acute hospital care? Is good quality palliative care provided in acute hospitals? In a recent study (Addington-Hall and O'Callaghan, 2009) a comparison of the views of bereaved people on the quality of care provided to their relatives in the last 3 months of life in hospitals and hospices showed that hospital care still remained less satisfactory with the quality of hospice nursing care being particularly appreciated. Certainly, this is reflected in my interview data with participants' experience of hospital being invariably poor. In considering this question, I reflected on my memo on 'not being listened to'. In the paper on local and cosmopolitan knowledge, Harvath et al (1994) had explained how nurses carried in themselves different types of knowledge. The authors reflect on the research of Tanner and Benner (1993) :

“According to their research, what distinguishes expert nursing practice is the application of the knowledge base to an in depth understanding of the patient as an individual. Expert nursing practice was characterized by a blending of scientific knowledge with an understanding of the patient's unique situation” (Harvath et al, 1994, pg 31)

Was this search for finding out what made hospices different to other places taking me back to the fundamental qualities of good nursing? Was this what made a difference to

service users and carers in respite care?

Of course, hospice care is not just about nurses and certainly for inpatient respite care, some service users and carers did say how they found the presence of doctors reassuring particularly where there was a concern that the service users health might deteriorate. The essence of hospice care is a multi-disciplinary approach and in what the authors describe as “the first study describing the core attitude in palliative care” (Simon et al, 2009), it is not only the nurses that appear to have the qualities that are so appreciated. I was particularly interested in the concept they identified as being a core attitude of “mindfulness” which is “often paraphrased with cautiousness, attentiveness, humility, and acceptance. It means non-acting, appreciating the other in his being.” (Simon et al, 2009, pg 409). I wondered if mindfulness was what the participants had picked up on in their observations. The nurse holds a unique role within this:

“No worker but the nurse can and will devote himself or herself consistently day and night to these ends. In fact, of all medical services nursing is the only one that might be called continuous.

This unique function of the nurse I see as a complex service” (Henderson, 1966, pg. 17)

Although Henderson speaks of the nurse’s role in terms of primarily nurturing the patient back to a state of independence, she also writes about the nurse’s role when nursing patients who have “irreversible illness, when dependence and death are believed inevitable”. Here she sees the main object of the nurse as being “to protect the patient from loss of dignity” during, as she refers to it, “this period of inescapable dependence...being alert to what gives the patient physical and spiritual comfort” (Henderson, 1966, pg 27). From this, I was also able to return to the data in my ‘not being listened to memo’ and found a connection with some of the words Henderson uses. She refers to the nurse’s role in providing protection from loss of dignity. I had identified a category of losing protection – the opposite of what should have been happening – but I

hadn't defined one of 'losing dignity' – how could I have missed that?

Henderson also makes a link between these fundamental principles and the work of Cecily Saunders and as such, one could say that the fundamental principles of nursing practice are also fundamental to a palliative care approach.

This extract demonstrates how memos provide a vehicle for making connections and seeing patterns from which abstract ideas can be developed. The connection between the two memos is not descriptive. It is not about the situations being compared like for like as it were. One memo is about the categories that emerged from the analysis of one scenario although themes from that scenario were compared with similar themes in other data during the memo. The second memo is about a category that overarched a number of themes that had emerged from initial coding to do with the preference for hospice care. The link as shown below in the diagram Fig.5.14, is between the ideas and concepts that the memos generated:

Fig. 5.14 memos generating concepts

'Not being listened to'	'preferring hospice care'
CONCEPTS	
<u>Needs</u> (not being met)	<u>Needs</u> (being met)
<u>Vulnerability</u> (loss of protection)	<u>Protection</u> (dignity and well being)
<u>Loss</u> (loss of dignity)	<u>Acceptance</u> (being a person)
<u>Risk</u> (to well being)	<u>Choice</u> (being allowed)

The memo 'preferring hospice care' generated concepts concerning needs, protection, acceptance and choice. Through writing this memo, I was able to recognise that I could develop the concepts in the first memo further to a more theoretical level which is in keeping with Grounded Theory analysis.

By this stage in my analysis, concepts were clearly beginning to emerge and the process of memo writing had helped this. There was still a need to be flexible in my approach to the development of concepts so as not to fall into the error of 'forcing' them. I still needed to be able to let themes emerge freely and analyse them accordingly.

#### **5.12 Theoretical sampling: refining the ideas**

Described by Charmaz (2006) as a "pivotal grounded theory strategy" which follows on directly from memo-writing, theoretical sampling is the way in which grounded theorists elaborate and refine theoretical categories that have emerged from their analysis (Charmaz, 2006) rather than increase the sample size (Charmaz, 2000). As I describe in Chapter 3, a pause in the analysis process (September 2009 – January 2010) provided an opportunity for reflecting on what I had done up to this point and what my next steps should be. It was in keeping with a Grounded Theory approach that once I had completed a first round of interviews with the participants, I questioned what I needed to do next. Glaser and Strauss (1967) define this time as one where the researcher can demonstrate their developing theoretical sensitivity by being prepared to let the emerging theory – rather than any pre-conceived plan which would stifle theoretical sensitivity – point to the next steps. It is therefore a time for questioning and following hunches

(Charmaz, 2006) so that further data collection in whatever form that might be, will illuminate categories and in turn lead to theoretical saturation.

In deciding where to look for “fresh data” (Cowley, 1990) and in keeping with the Grounded Theory method, I returned to the literature to develop my initial review further as described in Chapter 2. Theoretical sampling was based on ideas sparked off by emerging themes, categories, and developing concepts from analysis of the data I had collected from the participants and from themes in the literature which included the most recent work on family carers of service users with palliative care needs (Gomes and Higginson, 2006, Smith and Skilbeck, 2008, EAPC, 2009, Grande et al, 2009, Hudson and Payne, 2009, Kellahear, 2009). This literature reflected some of the emerging themes from my interview data including ambivalence, complexity, tension, the domination of the reactive repair model, relationships and the relevance of social networks. Therefore, rather than increasing my sample, I was drawn towards returning to the participants to ask them further questions and inquire about experiences that I had not covered before (Charmaz, 2006).

I was keen at this point to ask each of my participants specific questions that I hadn't asked before which related to the themes from the literature. The first round of interviews had been unstructured and I had collected a great deal of data about their experiences and perspectives of respite care within the context of their stories about caring and being cared for. Now, I wanted to return to the participants with some specific questions that were inspired by the literature and which for the most part, I didn't believe my existing data had answered. These were as follows:

**Do you have any ambivalence about accepting respite care?** This question had been answered indirectly in many ways in the first interviews but I wanted to try and ask the question quite baldly to further clarify what seemed to me to be a fundamental issue in terms of respite care being key to supporting carers of people with palliative care needs.

**Do you ever worry if anything might happen to the person you care for when they are in respite care?** I asked the cared for person this question as well in terms of whether they worried about whether anything might happen to their carer while they were in respite care.

**Do you think it would be helpful to be able to go for respite care where the service is only provided for people with this particular condition e.g. Parkinsons Disease or COPD?**

I also asked them to complete the social network circles exercise as described in Chapter 3. For the purposes of theoretical sampling, I was approaching the meetings with the participants with specific questions in mind that I wanted to ask and specific tasks that I wanted to do. I felt very aware at this stage that what was important now was to focus on the relationship between the carer and the cared for person and the relationships that existed around that. I had developed categories about the meaning of respite care in the context of the participants' worlds as they experienced them and memo writing had led to the generation of concepts that indicated that the experience of respite care was complex and deeply affecting. Social processes such as needs being met and needs not being met, being vulnerable, losing protection, building relationships, and being accepted were all emerging within the context of respite care. A theory was starting to develop so the task at this point was to elaborate and refine the developed



categories until their properties were exhausted and theoretical saturation could be achieved.

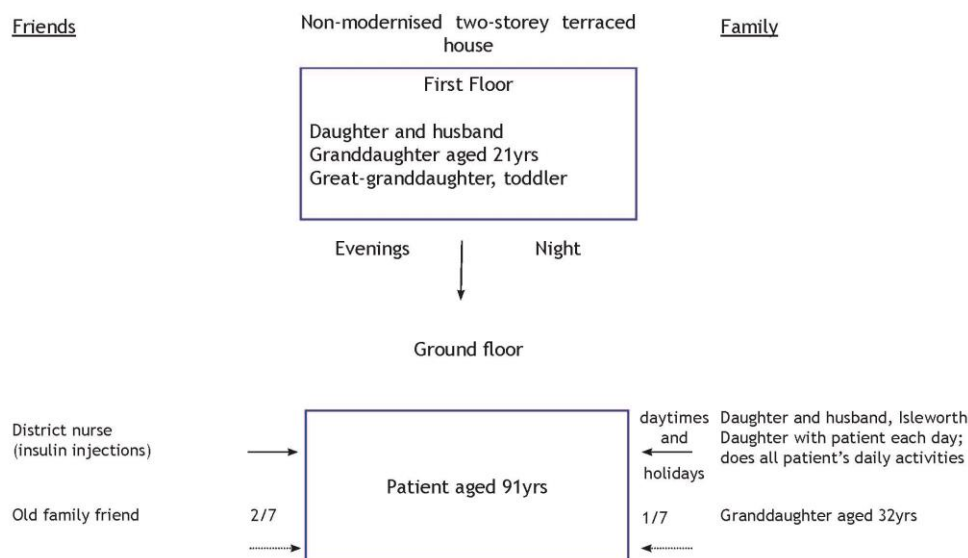
### **Social network circles as a component of theoretical sampling**

In introducing this section, there are two important points to be made. Firstly, the social network circles should not be confused with the simple concept map circle diagrams that I use frequently in the coding process throughout this chapter to capture emerging themes and which I explain in Section 5.5. The social network circles activity was part of theoretical sampling and a purely stand alone exercise based on social network theory (Barnes, 1954) as described in Chapter 3 (Section 3.7 Theoretical Sampling). The second point is to do with the thinking and process behind this approach which is explained in Chapter 3, Section 3.7. It is important to reinforce here that all of the participants were happy to take part in the exercise but while I had hoped that they themselves may want to use the materials I had provided to express themselves in whichever way they wanted to ie use the colours, shapes or highlighters they wanted to use, they were in fact reluctant to actively do this themselves. The process was therefore characterised by the participants directing me in how they wanted the social network circles to be presented. In terms of where certain elements of support should sit in the circles and what colours were used for example, I would describe this as a joint process with the participants showing me where they wanted things to be put and me scribing, suggesting and checking with them as we went along. An example of how this worked can be seen below in Fig 5.16. Here I describe how in Dick's social network circles, the colour that was used most was red and that this had come about as a result of the process and the way Dick was describing his situation to me in what I felt was such "an urgent and desperate way". My use of

the colour red was therefore a visual reflection of my attempt to capture the feeling behind the data I was collecting from Dick in this activity. In this way, the social network circle activity was not literally coded by the participants but it was done by me in active collaboration and participation with them. Analysis of the social network circles was concurrent with coding of the fresh interview data and all data was analysed in line with the constant comparative method.

Capildeo et al in as far back as 1976, advocated the use of a “social network diagram” in the care of patients with strokes, which could show at a glance the patient’s social network and the support he or she received at home (Capildeo et al, 1976). The authors had observed that successful discharge home from hospital was often hampered by lack of knowledge of the patient’s social environment and recommended the early completion of such a diagram to facilitate speedy discharge and to save on unnecessary reports having to be done. Fig 5.15 below is typical of such a diagram:

Fig 5. 15 Social network diagram and description (Capildeo et al, 1976, pg 144)



*“Social circumstances-*The patient was a widow living on the ground floor of a two-storey terraced house owned by her son-in-law. Her part of the flat, to which she was confined, was not self-contained and consisted of bedroom, sitting-room, outside lavatory, and kitchenette. The social network diagram shows strong social ties. Upstairs was her daughter, who had recently developed diabetes, son-in-law, granddaughter, and great-granddaughter, who all helped to look after her, especially at night. During the day another daughter came to look after her, doing the shopping and household tasks; both daughters were able to give insulin injections when the district nurse could not visit. The rest of the available family members visited at least weekly. Clearly the family had made all the arrangements necessary to look after the patient.” (Capildeo et al, 1976 pg 144)

I draw attention to this now as it sharpens our understanding of the challenges of the caring relationship reflected in the social network circles drawn by the participants in the study. It also reminds us of the social changes which have taken place since 1976 which have effectively led to carers becoming increasingly

isolated and reliant on interventions such as respite care to provide them with the support they need.

The recent family carer palliative care literature acknowledges the passing of such a time as described above but at the same time, there is something of a call to arms about how reliance on professional services i.e. for interventions such as respite care, will simply not be enough “to meet all end of life care needs” in the future (Monroe and Olivier, 2009, pg 16). They go on to say that there must

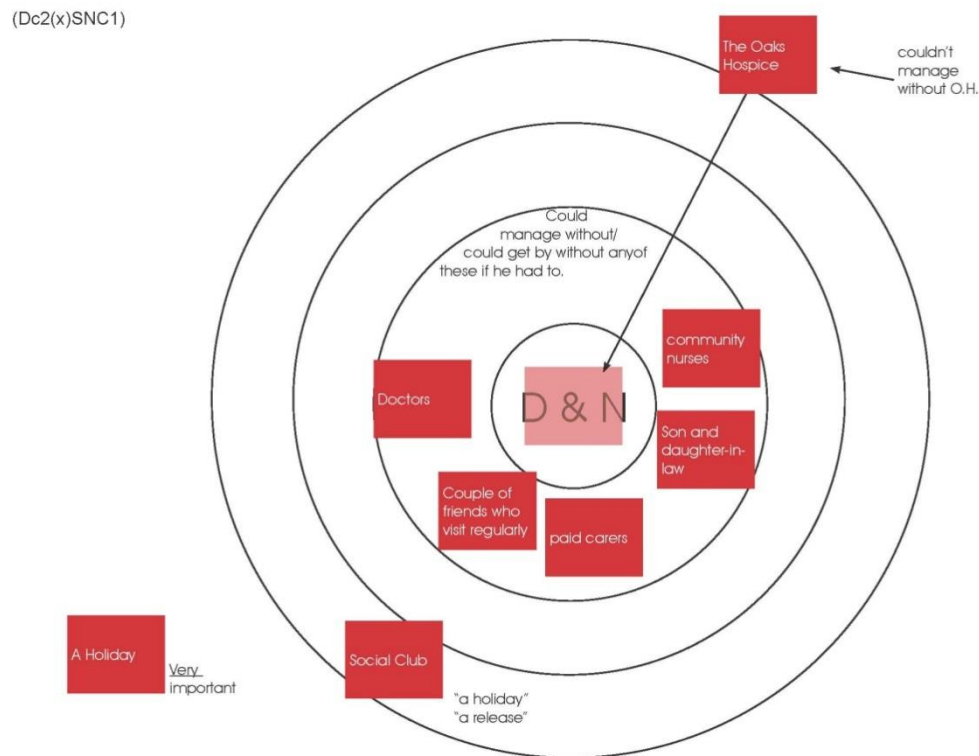
“... be a focus on altering public attitudes and enhancing family and community resilience and capacity, so that families and communities themselves are resourced and enabled to respond sensitively and compassionately to the needs of the dying and the bereaved.”  
(Monroe and Oliviere, 2009, pg 16)

The social network circles as drawn by the participants in the study reflect a world which appears to be caught in the challenges described in the literature. Where family support is, through no one's fault, limited or non-existent and for the most part, not expected, and the most valued and consistent professional support comes from the hospice which itself is limited. In this way, in terms of theoretical sampling, the social network circles had enhanced the relevance of the literature and vice versa, together leaving more questions unanswered than answered.

The drawing of the circles did bring something new to the data collection and there was evidence that it helped to clarify some of the participant's thoughts. Following completing the exercise with the carer Dick, he reinforced to me again that in spite of the fact that respite care isn't straightforward for him in that he still worries about Nora and still visits her if she is in the hospice, respite care at the hospice is still “very important”. As you can see from his diagram below (Fig.5.16) which incidentally, ended up coloured mostly in red because it felt so urgent and

desperate, he places the hospice right in the middle of the circles – he actually wrote directly on top of the D&N making it the most important component of his social network.

Fig 5.16 Dick's social network circle



He stressed that although he has the doctors, regular visiting friends, paid carers, his son and daughter-in-law and community nurses all in the second circle together and therefore all equally important, he could manage without all of those if he had to, but he could not manage without The Oaks Hospice. He includes the social club he goes to when he can as being on the outside of his support structure but nevertheless, it is like "a holiday, a release" so it is important to him. Even more on the outside – mainly because he didn't have one very often, he wished me to include a holiday which he said was "very important" as well.

As if freed up from the experience of completing this exercise, in answer to my confirming with him afterwards that despite him being a bit ambivalent about

respite care in terms of how much rest he actually got, that it was still very important to him, he then went on to summarise the issues around it for him as if he was really trying to get these points over to me once and for all. I have added the categories that came from focussed coding in the extract (Fig.5.17) below:

Fig 5. 17 Focussed coding in theoretical sampling

categories	transcript
Pinning hopes on the hospice  Respite making life a bit easier Still being needed Still being there  But being able to rest Not having to be on duty  Going away Not worrying Being out of my hands Nora being in good hands Feeling good The Oaks is the only place for respite Not being an alternative  Other options being too expensive  Family and friends willing to help  Not wanting to put on people  Family and friends willing to help Being worried  About something going wrong  Worrying about Nora Being without him Not being there Being indispensable Being responsible Nora panicking	<p>Dick: My only hope is The Oaks Hospice, that's my sole hope and as much as like if I didn't go away, I would be visiting every day, which doesn't make life easy, but it's a bit easier; or she'd be ringing up for something that she wants and I would whip it down straight away more or less. So if Nora went into The Oaks and I did go away, although that's not easy, because I'm not there I can't do anything, but if I was at home I'd have to do it. I'm still grateful that I can go to bed of a night without having to attend to medical problems.</p> <p>If I do go away, well I don't have anything to worry about as such because I can't do anything about it. <u>But I just know she's in good hands so that makes me feel good.</u> So my only respite is The Oaks. I don't have any alternative whatsoever.</p> <p>I can't get people in to do it 24/7, I could but that would be very very expensive, and I can get family and friends in who would willingly come in, but they've got lives to lead and I don't like to put on people. The problem I have I don't like to push it onto somebody else. As much as they would do it for a few hours; if I went away for 7 days and I'd be thinking I hope everything's okay, and do they know what to do if something goes wrong? And then of course you have to look on the other side of the coin, where Nora was concerned, <u>I'm not there, I'm her right arm and I'm not there and nobody can do it as good as me.</u> So will she start getting the panics on and bla bla and this and that and the other, and so that wouldn't work. So that just leaves me with one alternative, that's The Oaks Hospice, simply</p>

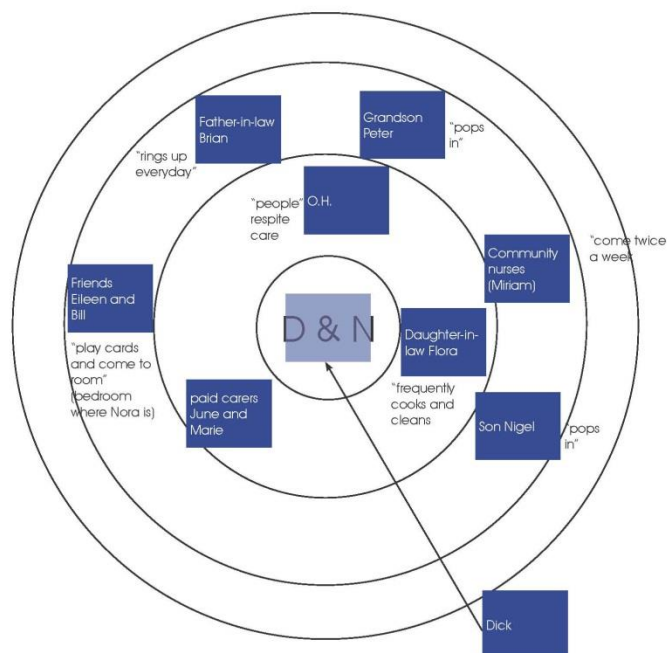
Being left with one alternative Being left with The Oaks Hospice Nora not wanting to go anywhere else	because she will not go anywhere else. (Dc2(x) lines 36-70)
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Within this extract, Dick covers a number of issues that are reflected in the literature. This suggests that there is a support network that would be willing to help but Dick doesn't expect them too – “they've got lives to lead” - and moreover, as he sums up in the identifying moment – “I'm not there, I'm her right arm and I'm not there and nobody can do it as good as me “ except The Oaks where he knows “she's in good hands so that makes me feel good”. The extract confirms that for Dick, respite care is very important but he has to “feel good” about the arrangements for taking over Nora's care and so does Nora otherwise her health will deteriorate and he'll be worried.

As ever, the data is rich. Dick's statement that his family and friends would be willing to help but “they've got lives to lead” reminds us of Capildeo et al's (1976) social network diagram and the massive shift in culture that has taken place since then. Clearly, the idea of family having “lives to lead” of their own was not part of Capildeo's (1976) matrix of care. However, the family and some friends clearly do have a role in supporting Dick and Nora which Dick acknowledges but Nora's diagram below (Fig.5.18) makes clearer:

Fig 5.18 Nora's social network circle

(Np2(x)SNC2)



In the narrative attached to the social network circle, Nora echoes Dick's view of the family's role in their caring arrangements:

Nora: "But Dick said it's always me (Dick) what's left to hold the baby. He said I could ring a doctor, I could ring one of the nurses he says but at the end of the day Nora, it's me you know just me. I mean if we had a different, a bigger family I suppose maybe more girls, but you see the families have got their own jobs to do haven't they?" (Np2(xi)Lines 125-133)

However, they are in contact and Nora talks about them all and the role they have in her life which may only be "popping in" or "ringing up everyday" but this contact is clearly valued and in her diagram, of equal importance to the community nurses who visit twice a week. This reflected me directly back to the literature and the public health approach to palliative care which Kellahear (2009) proposes as an alternative to focussing on interventions like respite care which he feels is not designed for prevention or harm reduction in the caring relationship. For Kellahear, it is Nora's social network that needs to be strengthened:



“Professional supports (i.e. respite care) do not address the everyday world of work, school, and recreational contexts of living and dying. Professional supports occupy only a slim body of time and interaction compared to the far more numerous relationships and time that people spend with their usual contacts and supports” (Kellahear, 2009, pg 28)

It remains at odds with Kellahear’s (2009) argument though that respite care with all its drawbacks is still seen as being “very important” for the carer – indeed the “sole hope” for Dick – and for Nora, although not quite as important. For Nora, respite care at The Oaks is all about “the people” and the care she receives which when it’s good, is really good and benefits both Nora and Dick as the following extract indicates:

Dick : “ When she was in The Oaks and I was away, and I rang up and she said “you’ll never guess what I’m doing, I’m playing bingo and having a glass of Bailey’s and thoroughly enjoying it”, which lifted me no end. But the facts of the matter is that one week prior to that, which is like any normal week in this house, you wouldn’t put any bet on of her playing bingo or having a glass of Bailey’s next week, because you would think it would be a nigh on impossibility. So from that angle, whoever organised a game of bingo and a glass of Bailey’s really wants a medal, and that’s it.” (Dc2(x) lines 94-107)

I mentioned this to Nora in my interview with her:

Anna: “... Dick did tell me, and I’m sure he won’t mind me saying, when you were last in, you rang him and said you were having a game of bingo and a glass of Bailey’s

Nora: Absolutely, (giggles) it was just brilliant, it was really good, I enjoyed that night particularly.” (Np2(xi) Lines 34-41)

I coded Dick’s words as ‘being lifted’ and Nora’s as ‘enjoying myself’ and it really reinforced to me how respite care can be mutually beneficial. Dick also hints at the fact that somehow, the hospice has motivated Nora to behave in a way that he wouldn’t have expected, indicating that the intervention of respite care has had a therapeutic effect on Nora at the same time as providing a break from caring for him. As an example of theoretical sampling, this exercise with Dick and Nora had

brought something new to my data in the form of a greater understanding of their support structure and where respite care sat in that. The associated narrative had added to the properties of a number of categories including the category of respite care 'being mutually beneficial'. Being able to relate aspects of this exercise to the literature also sparked off theoretical insights and the depth of theoretical possibilities was increased in the interplay between the participant data and the literature.

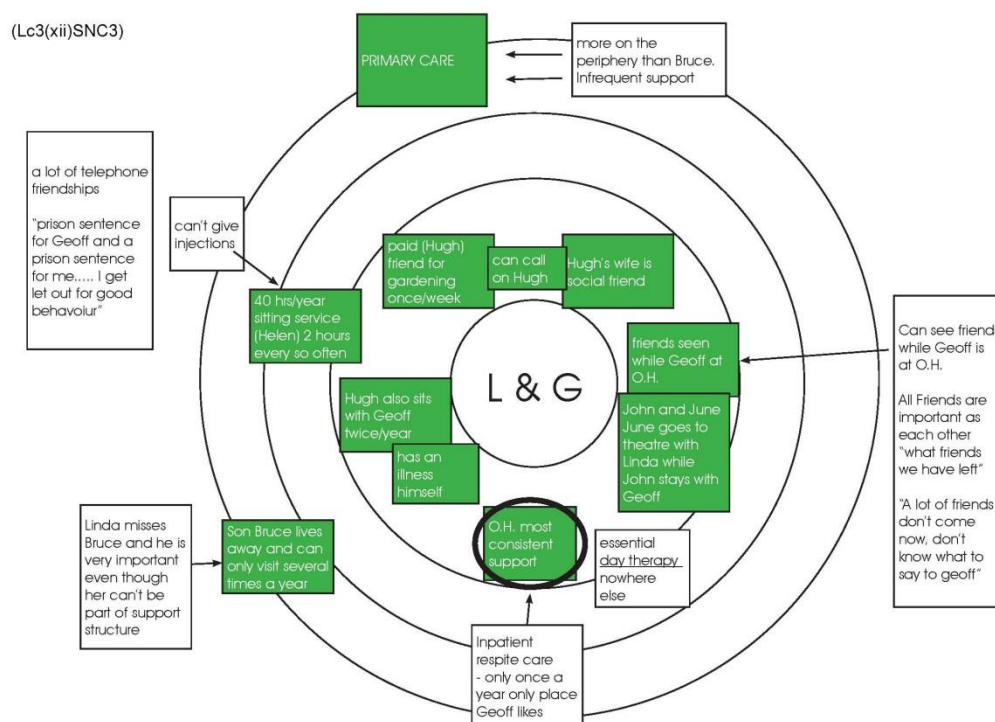
As the palliative care literature reflects an increasing focus on the importance of patients being able to die in their preferred place of care free of unnecessary hospital admissions (Leadbeater and Garber, 2010), Kellahear (2009) is not alone in having misgivings about the value of respite care in its current form for palliative care service users and carers (Hudson and Payne, 2006, Smith and Skilbeck, 2008) and a recurrent theme in the recent literature is the importance of strengthening the family and its social support networks (Gomes and Higginson, 2006). Monroe and Oliviere (2009) add to this:

“There must, therefore be a focus on altering public attitudes and enhancing family and community resilience and capacity, so that families and communities themselves are resourced and enabled to respond sensitively and compassionately to the needs of the dying and the bereaved.” (Monroe and Oliviere, 2009, pg 16).

As I progressed through the social network circle exercise with the participants, I was struck by a recurring theme which was the social isolation experienced by the carer and the cared for person, and the apparent lack of “community resilience” (Monroe and Oliviere, 2009) which might help to make respite care less important. Whereas Nora and Dick appear to have maintained some level of informal social support network which may well be influenced by their particular locality, I found

that 'losing friends' and 'family living away' was by far the most commonly reported experience as the reader will see from Linda's diagram (Fig.5.19) below:

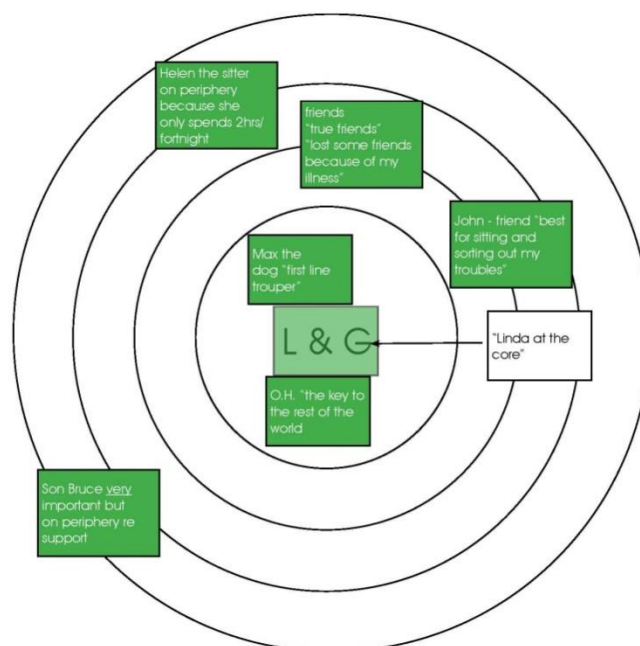
Fig 5.19 Linda's social network circle



For Linda, her friends are shown to be the most important part of her social support structure along with The Oaks Hospice day care (respite) which she describes as “the most consistent support” which she can’t get anywhere else. However, although her friends are very important to her – even “a lot of telephone friendships”, she goes on to say that all of her friends are as important as each other – “what friends we have left”. And she adds that “a lot of friends don’t come now as they don’t know what to say to Geoff”. In his diagram (Fig.5.20) below, Geoff confirms this and talks about how important his “true friends” are i.e., the ones he still has:

Fig 5. 20 Geoff's social network circle

(GP3(xiii)SNC4)



Interestingly, along with another service user, Geoff places his dog in the first circle of his diagram and describes him as a “first line trouper”. His wife is very much at the core of his diagram and the hospice is also very important. For Geoff, who in the associated narrative to this diagram describes himself as being like “a prisoner”, “frustrated” at not being able to get out (Lines 84-85) he poignantly describes the hospice as “the key to the rest of the world”.

Both Linda and Geoff wanted to tell me how important their son was and Linda said how much she missed him, but because he lived and worked so far away, he could only be on the periphery of the social support structure.

Other participants reported a similar picture with regard to friends and family while we were drawing the diagrams. Anita commented on society as a whole not helping in that people had often stared at Tom – “not understanding” - and would often ignore him if they saw him. She said that it didn’t seem to bother Tom but it

did affect their life. “No friends that are a support – you lose a lot of friends – it’s amazing how many you lose” said service user Greta who thought this was probably “because you can no longer do what they do”. Anita explained that “friends disappeared – even family they were scared, they didn’t want to be upset...didn’t know how to treat it (Tom’s illness)”. Mary concurs with this – “Incurable disease upsets people”. She goes on to say “It would have been nice for someone to drop in- just to take Ron out but no one ever did. People don’t know what to say.” She adds sadly and succinctly, “your world shrinks – you can’t expect to be included”. This reminded me of the category ‘feeling left out’ which I had developed from the first interviews with carers and I felt that ‘feeling left out’ and ‘not being included’ could be drawn together in a category, ‘being isolated’. The cared for person is isolated as well but at least they have ‘a key to the rest of the world’ in the form of the hospice and most particularly, day care. Similarly, with other categories, the process of theoretical sampling was helping me to draw the threads of my research together towards theoretical saturation.

### **Asking specific questions as a component of theoretical sampling.**

Although asking targeted questions of participants as part of theoretical sampling is considered to be entirely acceptable (Morse, 2007), I found this more informational and directed style of interviewing to be somewhat at odds with the more intensive interviewing style I had adopted for my data collection so far (Charmaz, 2006). Other than being about the experience of respite care, the previous interviews were characterised by my being open to exploring a substantive area, allowing the concerns of the participants to guide the emergence of a core issue (Holton, 2007). On coding the data I collected from these interviews and reflecting on how successful I had been in achieving what I had set

out to do, I was interested to find that even with asking more targeted questions, the participants had still been able to open up the subject as it were and explore it rather than simply answer the question. These interviews were also an opportunity to collect additional information about areas of the participants' experience which I felt I had not explored fully before and ensure that they had been able to tell me everything they had wanted to. Theoretical sampling in this case was used to refine categories and develop further theoretical insights.

### **Do you have any ambivalence about accepting respite care?**

I have given an example of an answer to this question in the extract from Dick above. This was the first of this round of interviews and I'm not sure that I asked this question very well. I had established with Dick that despite all its drawbacks as he had identified them, respite care was still "very important" to him. I went on to put to him that although he might feel a bit ambivalent about respite care, it sounded like he didn't have an alternative. His answer was better than my question: "There is no alternative, and I haven't a clue what ambivalent means" (Lines 29-30). There is clearly a lesson to be learned here on the part of the researcher. We laughed and I went onto explain it as 'pros and cons' and Dick answered my question with a full answer that touched on 'being worried' as well as many other concerns. What I really took from this was that if I had put myself in Dick's shoes, I might have actually thought that may be 'ambivalence' is something of a luxury. There was no weighing up to be done as far as Dick was concerned – he knew what helped him and where Nora liked to go – respite care at The Oaks - and that was his "sole hope". So there was no weighing up to be done and there were no choices to be made. Nora later on reiterated that she had no worries about coming to the Oaks but there was "nowhere else" she would

consider. She did give some indication that others might be more ambivalent though:

Nora: "Oh no I never have any worries when I go into The Oaks. I mean it doesn't frighten me or anything. Because I mean people say 'oh The Oaks, you go in there, you never come out'. I say don't talk stupid, you do come out! I mean I've been in loads of time and I'm still home, I come home. I don't want to come home like but I come home. (*giggles*) Yeah I do" (Np2(xi) Lines 56-64).

It is interesting in that this place that is so highly valued by the participants in this study, is still a place that people who haven't been to, still fear. I coded this as 'not worrying about having respite care at the hospice' for Nora and Dick.

Service user Geoff is not ambivalent about accepting respite care at the hospice – "Yeah, I like the people that are there" (Line 28) but he does have reservations about the Nursing Home - NH2 - which he went to recently:

Geoff: "Money grabbing, not really interested in patients or inmates that have got problems. I just feel there are a lot of places like that, that take whatever they can out of the situation and turn it towards their own good" (Gp3(xiii) Lines 40 – 44)

He goes on to say that staff there are not "sufficiently knowledgeable I suppose" (line 47) and that he doesn't like places that are "regimented and ill founded" (lines 57 & 59) hinting at a lack of person centred care. This made me think of my memo – 'who has the knowledge?' and that really, it is probably the case, that the more service users and carers can trust a setting, although they may have underlying ambivalence about being apart from their loved one, the less ambivalent they are going to be. Service user Greta and her husband would prefer not to be apart at all but they have no ambivalence about the hospice's care. However, for Anita, a bereaved carer, she told me that she was not ambivalent about her husband

having respite care at the hospice – she was “happy” because Tom was happy and, reminding me about what a luxury ‘being ambivalent’ is, she adds that she still felt “guilty” leaving him at the hospice – “but I needed it” (Line 17). Anita felt very strongly that regular and frequent respite care at the hospice would have really helped her but she was scathing about some of her other experiences in other settings:

Anita : “I would say to people ‘will you go and visit him?’ whereas at The Oaks, I never thought about that. Go and visit him just to keep him sweet and make sure that he’s okay. Because they’d treat him like an imbecile and I used to go particularly and say ‘When Tom comes in would you please keep him stimulated’, but they didn’t you know. I said ‘speak to him, and if he can’t understand he’ll be able to tell you with his eyes’. I said ‘he’s a very intelligent man and he’ll know exactly what you say and please don’t just leave him sitting in a chair, put him with the television on or play a game with him or do a puzzle” you know?” (Ac2(xv)Lines 94-107)

Fig 5.21 below indicates properties of the category ‘being ambivalent accepting respite care’. With a care setting where there is trust and the staff have knowledge, the ambivalence is reduced. This diagram relates directly to and includes the category of ‘being apart’:

Fig 5. 21 ‘Being ambivalent about accepting respite care’





**Do you ever worry if anything might happen to the person you care for when they are in respite care?**

'Being worried' emerged as being connected to 'being apart' but without question, a high quality of care led to participants feeling less worried therefore 'being worried' isn't always associated with respite care. There was evidence though that 'being worried' was not specific to the carer. When apart, Geoff said that his main worry was:

"if something was to happen whereby Linda cannot carry out her wishes as far as my welfare is concerned. Very few people around us in a sort of caring mode." (Gp3(xiii) lines 74-78)

This is understandable as carers often do have health problems themselves and Geoff is worried about who would look after him should anything happen to Linda. Service user Greta told me she didn't worry about her husband when she was in respite care in The Oaks because she rang him every night "to see if he's alright" and sometimes during the day as well, and although there were drawbacks to respite care at the hospice, and she and Steve would rather have respite care together, she did enjoy her break and was not worried about being away from him:

Greta: "No, no I have gone to respite care for quite a number of years and as Steve's got worn out shall we say, he'd needed that break and he doesn't mind me going there so

Anna: So it's not a worry for you?

Greta: no it's not a worry at all, and all the staff are great so you can have a laugh with the staff

Anna: is that at The Oaks?

Greta: Yes it makes it more like a family, friends and I don't know I mean they are all good nurses and that but they'll say 'come on like

it's time you were up now' jokingly or 'are you going to stop there all day? and like they know I like a bath so it's a bath I get every day

Anna: Oh lovely

Greta: And a Jacuzzi one and it's lovely because I don't have a bath I only have a wet room at home

Anna: so that's a real treat for you?

Greta: yeah, yeah so they like give me a treat every day, they try and fit it in everyday" (S7G2cp(xvi) Lines 76-96)

Her husband acknowledged that there is always a worry that Greta's health might deteriorate, but both Greta and Steve appeared to accept this. Indeed, Greta explored this further by telling me that when she was in the hospice for respite care, she had been asked whether she wanted to be resuscitated in the event of collapse:

Greta:..."when they ask you about you know, resuscitating and all that and I said the first time, I said no I've got a lot of living to do, and I know that last time I changed my mind and they came and asked me twice if it was right because I'd said I (struggling for the word)

A: You did want resuscitating?

Greta: But I said no. I said I think now if I had a heart attack I think it's Him up there telling me it's time to go!" S&Gcp2(xvi) Lines 112- 120).

This sense of accepting and trusting in the care being provided was reinforced by the fact that Greta told me that Steve's only concern was that The Oaks would let them know if anything was to happen to her. They both felt the hospice would, but Geoff had had a friend whose husband had had a heart attack in a home that they used for respite care and she had not been informed. I coded this as 'feeling unsettled'. It's as if the carer and the cared for person develop a certain resilience to cope with their situation i.e. strategies like being able to joke, being accepting, checking to see if each other are alright, trusting the care being given. But then something like someone not being told that their partner had had a heart attack

has an unsettling effect and can undermine that sense of feeling safe and secure. I developed a code of 'losing confidence' from this.

There was no question for Linda that she worried that something might happen to Geoff when he was in respite care other than in the hospice. I asked her if she was concerned whether Geoff's condition may deteriorate while she was away:

Linda: "Well I think it always does,

Anna: Right

Linda: I think, well I think, well every time he's in hospital it seems to deteriorate. I mean it's so bad while he's in hospital, I wonder how I'm going to manage when he comes out. But he obviously picks up a bit, just because he's in familiar surroundings. He wasn't happy in NH2, and I think they bullied him a bit over what he could and couldn't do. He didn't like the fact that they wouldn't let him have coffee in an evening. (Lc3(xii) Lines 43-51)

I believe that this experience was the one that Geoff was referring to when he said the care was "regimented".

This sense of 'feeling unsettled' and 'losing confidence' in a care setting was evident in one of the bereaved carer's responses. Once this had happened, she became very worried about her husband having to have respite care even at the hospice. The occasion which was related to the hospice concerned staff ringing Mary to say they were worried about a certain aspect of her husband's personal care. This had led them to think that she might not be coping with looking after him. The fact that a member of staff had called her when she was away with her family – "fortunately I was in England" – really threw Mary and her family. Firstly because she was always very careful with this aspect of Ron's care so was taken aback when the suggestion was that she wasn't, but also, receiving the call when she was supposed to be having a rest, enjoying some time away with her family,

had unsettled her. The call also came at night – “quite dramatic...’we’re glad we’ve got hold of you’...” (Line 64). This incident had long term consequences for Mary and she continued to worry about it:

Mary: “I tried to ignore it....but it made me think now, I’d better, you know, if he does go again, or if he goes anywhere, I have got to watch this... but it was out of the blue, it was odd” (Mc2(xiv) Lines 81- 87).

I reflected on this and it made me think about the discussions I had had with staff about respite care (Chapter 5.8) – “In order for staff to recognise the full importance of respite care, they need to see it in the context of the external and internal experiences of the service users and carers as they are living them in their worlds.” This incident had really unsettled Mary – I coded it as ‘being unsettled’, but my feeling was that the staff member who had made that call had no idea about the effect it was going to have on Mary and I feel fairly confident that they had thought they were being helpful. I think what this member of staff had shown was a lack of sensitivity or understanding of the world as Mary was experiencing it. Thus he or she had completely misjudged the impact of their call and their comments. I coded this as ‘staff not being sensitive’.

Mary explained that although this incident made her worry about Ron having respite care, it did not affect Ron who remained unaware of any problem. However, the next incident which Mary reported to me did have an impact on him and for me, in analysing this data, I felt it probably came from a similar lack of sensitivity. In this case, while in respite day care in a care home, Mary explained to me that Ron had been accused of behaving inappropriately with another resident. This was intensely upsetting for both Mary and Ron and the way she described the impact it had on Ron was very powerful. Mary said that this accusation had upset him because it was “aimed at him personally” (line 133) and as a result of it:

Mary: “.... he wept and said ‘nobody will ever take me again’ you see. And he did go somewhere after that, and how he felt I don’t know. He did not refuse to go but it was more of a discussion, and I could tell that he was not all that willing.” (Mc2(xiv) Lines 139-143)

I have underlined the sentence above as for me, this was an identifying moment. This short sentence is full of distress and sadness and it is powerful because I think it allows the reader, should they wish to, to briefly enter into Mary and Ron’s world, and feel the sharpness of their distress and how desolate Ron must have felt. What follows are Mary’s observations of how this may have come about. She says of staff in care settings:

Mary: “And they (staff) forget that when people go into respite, and they continue to go to the same place or go to a day centre, week after week after week, they are like little children in that it becomes like their family, their second family. Therefore in a way the carers, sometimes without knowing, treat them like their family and they say things maybe to them that are quite, well not intimate, but you know..

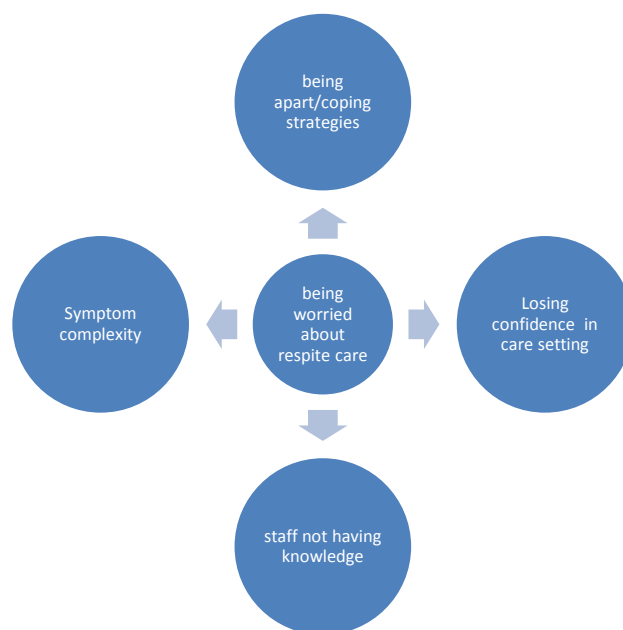
Anna: Well I think intimate, you are right....

Mary: ‘she’s doing that; she likes you’. ‘That lady likes to sit next to you’ and that, and they become a family which really calls for these more intimate things to be said, to be done, you see?” (Mc2(xiv) Lines 227-234)

This demonstrates what a complex process caring for vulnerable people is and the damage that can be caused through a lack of understanding of and sensitivity to that complexity. As Mary points out, “whether it’s down to experience or qualification, I don’t know, maybe both” (Lines 257-258). Mary and Ron’s distress was not helped by the apparent lack of skill with which the situation was handled which showed little sensitivity to the complexity of Ron’s needs and for example, issues around his complex Parkinson’s Disease medication regime and associated side effects which may well have played their part in any inappropriate behaviour Ron had shown. In terms of theoretical sampling the analysis of this data helped

me develop further theoretical insights into the category of ‘being apart’ and its properties of ‘losing protection’, ‘being at risk’, ‘being vulnerable’, ‘building relationships’ and in turn ‘being worried’ about respite care. Probably, most clearly, it draws these themes together in an overarching concept of ‘being vulnerable’. As Mary says, when staff at the home were addressing what had happened – “and there was Ron - *utterly* vulnerable; very, very vulnerable..” (Line 274). Fig 5.22 below shows the factors that influence the extent to which service users and carers worry about respite care:

Fig 5.22 ‘Being worried about respite care’



**Do you think it would be helpful to be able to go for respite care where the service is only provided for people with this particular condition e.g. Parkinsons Disease or COPD?**

I included this question as recent family carer literature has started to give consideration to carers of people with advanced organ failure and neuro-

degenerative disorders; conditions which, the authors say, currently receive little attention from hospices or palliative care services and pose specific care-giving challenges (Brown and Addington-Hall, 2008). Disease specific respite care is discussed. Firstly, participants made me aware of the fact that such places for respite care do exist locally but are not accessible due to them being very expensive, which raises questions in itself.

Anita: "Yes well I mean there is one, the (names place) and that was beautiful and I would have been happy but it was far too expensive and I don't think the council were prepared to help me fund it or whatever, but that would have been a lovely place..... And they did things - they had physios there and they did treat them like human beings and it was a beautiful place but no we couldn't afford that."  
(Ac2(xv) Lines 135-145)

However, for the most part, there were mixed feelings about how helpful this would be. For the service user who had COPD, she and her husband felt it would be very helpful to be able to be with people who had COPD so that they could all learn from each other's experiences. On the other hand, the service user with MS felt that one of the things that can be distressing about such places is that you see people who are very deteriorated and you wonder how long it will be before you become like them. She also pointed out that MS is very complex and as no one person is the same as the other, she wondered just how beneficial it would be. This was also pointed out by the service users and carers who had Parkinsons Disease. They also thought though that some specific expertise in the disease would be helpful. Generally speaking though, there was a feeling that because symptoms were complex and every person was an individual, what mattered most of all was without doubt having a knowledge of the disease, but also 'knowing the person'. I suggested this to Mary who agreed and added that the hospice where

Ron had had day care had never had any problems with meeting his needs appropriately as far as Mary was concerned:

Mary: So you see I'd find that it was okay, and honestly I had no qualms about that. You know in some ways I think they knew him better than I did, (laughter) they saw a different side of him as well you see, and there was time to get to know. There was all this getting to know one another thing as well and he'd talk about his troubles - not very good today, something is worrying him Mary, and I'd say oh yes it's probably such and such or so-and-so and we'd sort it out. No it was lovely. I didn't feel that, ever feel that they didn't understand his disease, honestly. But you see they've got quite a few with Parkinsons, I was quite surprised

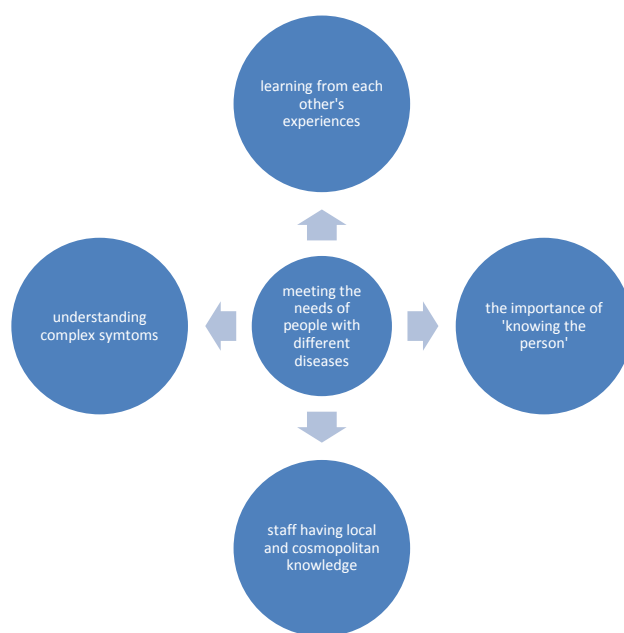
Anna: Yes that's true

Mary: and I thought if they don't know about Parkinson's now they never will! (laughter)" ( Mc2(xiv) Lines 377-393)

Clearly, there was a limit to how much I could explore this question as I think only one of the participants had had experience of such a setting. However, in developing the themes from the responses to the questions, I developed the category, 'meeting the needs of people with different diseases'. Within this, properties such as the importance of 'knowing the person' and 'staff having local and cosmopolitan knowledge' emerged which were features of memos as described earlier in this chapter and as shown in the diagram (Fig.5.23) below:



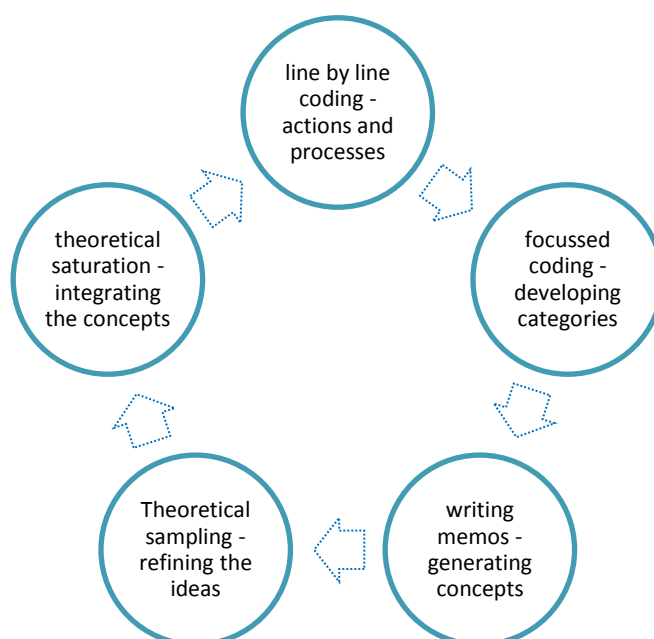
Fig 5.23 'meeting the needs of people with different diseases'



### 5.13 Theoretical saturation: Integrating the concepts

The diagram below (fig. 5. 24) shows the process by which I have reached this point in the process of analysis.

Fig 5. 24 Coding processes in Grounded Theory



The diagram demonstrates that although Grounded Theory analysis follows a logical process, one can always return to the data if new theoretical insights are sparked off. Dotted line arrows indicate that the process may not be quite so cyclical as this all of the time and as I have described before, there can also be many influences on the characteristics of each stage. This is reinforced through the use of text on a clear background in the circles rather than a filled shape. But it is the adherence to this logical process in Grounded Theory which contributes to the trustworthiness of the findings (Coyne and Cowley, 2007) and ensures that coding ultimately rises above the descriptive to a theoretical level which can truly illuminate the phenomenon we are studying.

Glaser and Strauss (1967) first described theoretical saturation as the point where the researcher stops sampling because there is no additional data to be found whereby the properties of a category can be developed. However, there is still much debate in the Grounded Theory literature about what theoretical saturation is and how you know you have reached it (Charmaz, 2000, Charmaz, 2006, Morse, 2007) or whether it is even possible to reach it (Dey, 1999). Charmaz (2006) gives some advice:

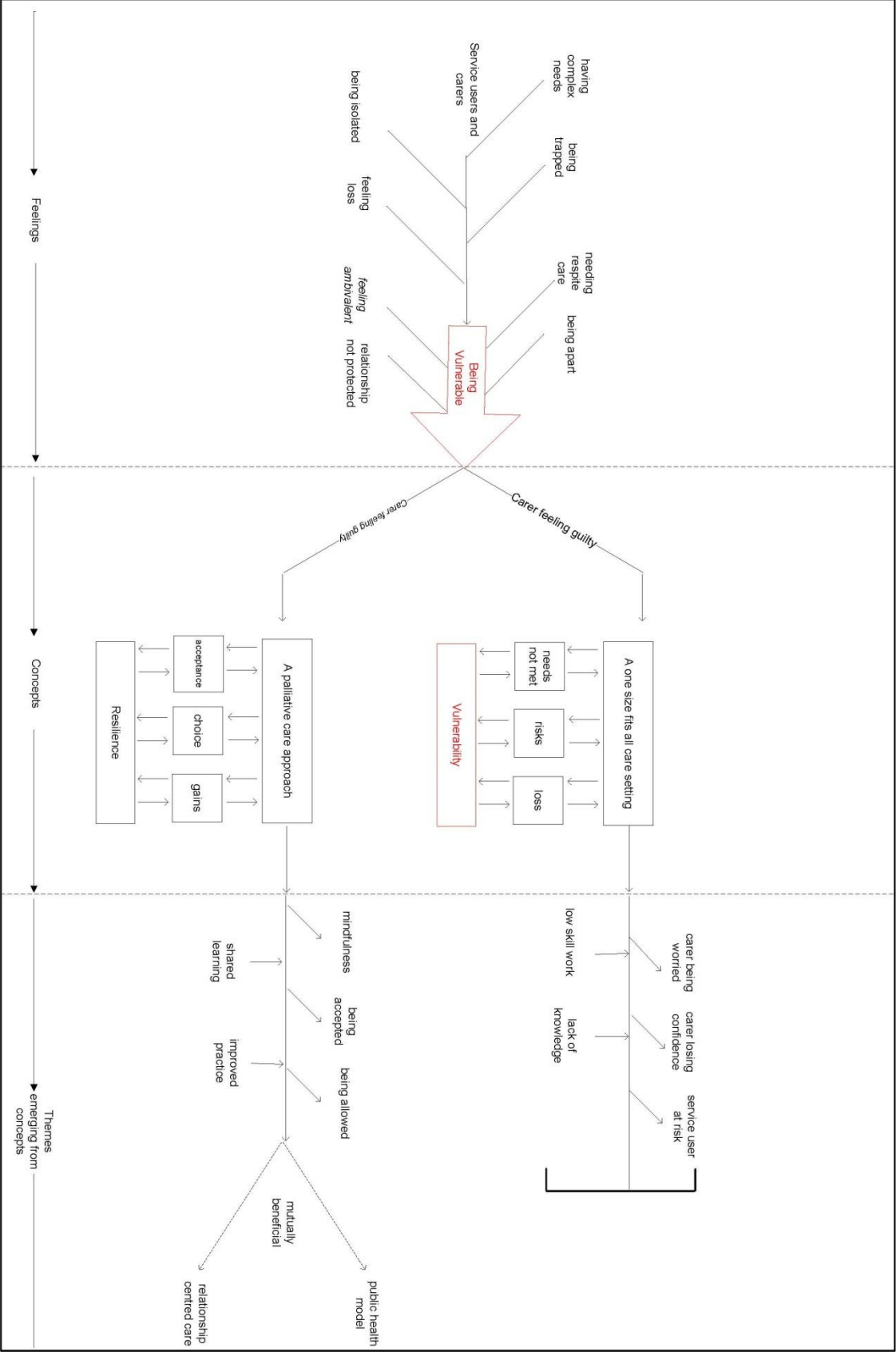
“Be open to what is happening in the field and be willing to grapple with it. When you get stuck, go back and recode earlier data and see if you define new leads. Use grounded theory guidelines to give *you* a handle on the material, not a machine that does the work for you.”  
(Charmaz, 2006, pg 115)

So that is what I tried to do and within the limits and aims of my study, I felt that I had developed each of the categories as much as I was able to. However, in sorting memos, notes and extracts from the study, I felt that there would always be

the potential to develop further theoretical insights and make new connections for future endeavours (Charmaz, 2000).

It is at this point in a Grounded Theory study that the relationship between categories is firmly established and abstract major concepts emerge from the data through which the findings can be reported and a theoretical framework developed. As I have explained before, Grounded Theorists often use diagrams to help with this process and many treat creating visual images of their emerging theories as an intrinsic part of the method (Charmaz, 2006). I have found the use of diagrams to be helpful throughout the analysis process and in keeping with this style I have developed a diagram (fig 5.25 see below), which is a visual representation of the integration of concepts defining the need for respite care in palliative care service users and carers and the implications of this expression of need. As such, it is a development of all previous diagrams and is naturally more complex than the simple concept map circle diagrams I have used previously. Findings from the study will be reported in Chapter 6 within the context of the concepts as defined in the diagram (fig.5.25) below:

Fig. 5.25 Diagram showing the theoretical integration of concepts in the need for respite care in palliative care service users and carers



### Explanatory notes for Fig. 5.25

I have presented this diagram of the theoretical integration of concepts in the need for respite care in palliative care service users and carers in the form of a flow chart. I feel this captures the processual nature of the need for respite care and the consequences of the expression of this need. In this way, it is in keeping with Grounded Theory analysis which emphasises the importance of actions and processes (Glaser and Strauss, 1967).

The diagram is divided into 3 sections. From a practical perspective, this aids clearer textual explanation. From a theoretical perspective, the sections provide an opportunity to add clarity to the diagram. An arrow line runs along the bottom of the diagram. This emphasises the processual nature of the illustration as described above and within the running arrow line, there is a word in each section which describes the content of that section and in turn, how one section leads to another. In brief, in the first section, the diagram focuses on the 'feelings' experienced by service users and carers in their journey towards needing respite care. In the central section, the diagram shows 'the concepts' which emerged through the theoretical development of memos which were developed from analysis of service users and carers experience of respite care. In the final section, the diagram shows 'themes emerging from the concepts' as shown in the central section of the diagram. A more in depth explanation of the diagram follows:

The diagram has at its core the central category of 'being vulnerable'. In the first section, we can see that codes relating to this category are common to both service users and carers and are shown in the diagram to be 'having complex needs'. The feelings associated with this are 'being isolated', 'being trapped' and

'feeling loss'. The category of 'being vulnerable' has been coloured red to indicate the risk associated within it. The visual representation of vulnerability is explained further in the next chapter (Section 6.3) and is shown as a diagram (fig. 6.1 The spine of vulnerability). The first section of Fig. 5.25 shows that the service user and carer are vulnerable and how respite care is needed by the carer. There may be ambivalence about this. '*Feeling ambivalent*' is written in italics to show that this may not always be the case as analysis has indicated. The diagram shows that needing respite care will mean 'being apart', 'and as such, strategies are not in place to protect the relationship.

In the central section, the diagram shows how theoretical development of memos generated concepts that related to what I have named 'a one size fits all care setting' and 'a palliative care approach' to respite care which service users and carers preferred. As the carer makes the decision to accept respite care, the diagram shows that the carer may feel guilty. In the journey towards accepting a one size fits all care setting for respite care, analysis showed that it was most likely that the carer would feel guilty. In accepting respite care provided in a palliative care approach, there was evidence to show that feelings of guilt can still be attached to this for the carer, however, it was much less likely because the respite care was more acceptable. The fact that there *may* still be feelings of guilt in this case is reflected in the diagram through the use of italics and a smaller font. The concepts which underpin a palliative care approach shown in the central section of the diagram are acceptance, choice and gains all of which have the potential to promote resilience. The diagram shows how a palliative care approach can be compared to a one size fits all care setting approach. The latter is underpinned by the concepts of needs not being met, risks and loss through which the concept of vulnerability, again depicted in red, is reinforced. The final section of the diagram

shows that the palliative care approach is characterised by concepts such as 'mindfulness', 'being accepted' and 'being allowed'. Through these aspects of care underpinned by shared learning leading to improved practice, analysis indicated that the palliative care approach was mutually beneficial to both service user and carer and had the potential to facilitate the development of relationship centred approaches as indicated in the literature and in turn a public health model of respite care.

The third section shows the themes which emerged from the concepts as shown in the central section. The third section shows that in a one size fits all approach, care is often characterised by the 'carer being worried', 'losing confidence' and the service user being 'at risk'. This approach is underpinned by a lack of potential for knowledge development and exchange in which the complex symptoms of the cared for person and the knowledge held by the carer of the cared for person are denied. Added to this, the expectation is that care can be provided within a framework of low skill. Alternatively, the final section of the diagram shows that themes which emerged from a palliative care approach to respite care were much more positive. In this case, respite care was shown to be characterised by themes such as 'mindfulness', 'being accepted' and 'being allowed' and the diagram shows that respite care in this situation could be mutually beneficial. Because of this and through shared learning and improved practice underpinning this approach, the diagram shows that a palliative care approach in respite care has the potential for development into new models of care such as relationship centred care (Nolan et al, 2001) and a public health model of care (Kellahear, 2009) where there is the potential for both family and community support to be strengthened. In comparison, the one size fits all approach with its lack of potential for knowledge development leads only to 'a dead end' shown in the diagram as a closed thick

black line. The themes related to the one size fits all care setting approach and the palliative care approach as depicted in the final section of the diagram are all explored further in Chapters 6 and 7. In addition, in Chapter 7, there is further exploration of the palliative care approach to respite care and how this could be developed into a 'new' palliative care approach which would have the potential to further enhance the experience and benefits of respite care for palliative care service users and carers.



## Chapter 6 Developing a theory: Finding meaning and interpreting the data

### 6.1 An interpretive approach

In keeping with the theoretical underpinnings of the research, it is essential that findings from the study are presented in a way that reflects a constructivist method within an interpretive approach as described in Chapter 3. As Charmaz explains, “constructivist Grounded Theory lies squarely in the interpretive tradition” (Charmaz, 2006, pg 130) and as such, it was important to me that rather than provide what might be narrow explanations of the experience of respite care, the findings should show the complexities of the participants particular worlds, views and actions (Charmaz, 2006) and within that, the possibility of multiple and complex truths (Sargeant, 2004). In developing interpretive theory, we are therefore encouraged to have an imaginative understanding of the studied phenomenon:

“This type of theory assumes emergent, multiple realities; indeterminacy; facts and values as linked; truth as provisional and social life as processual” (Charmaz, 2006 pg 126).

A constructivist approach reinforces the interpretive methodology by not only *showing* the complexities of the participants’ worlds but also recognising that data and analysis is created from the shared experiences and relationships with the participants and other sources of data (Charmaz, 2006). Within this, as Mills et al (2006) explain, “the researcher openly acknowledges his or her own role of authoring a story of the shared experience of meaning-making about issues of importance for participants” (Mills et al. 2006, pp.11-12). As such the process of

finding meaning in the data and developing theory is in keeping with the theoretical underpinnings of my research:

- learning from the experiences of service users and carers
- embracing the principles of critical practise
- learning through 'relational endeavour'.

Therefore, it will not be the aim of this chapter to invite the reader to look on as I reveal in all its glory, some grand objectivist truth about the value of respite care to palliative care service users and carers. Rather it will be an analytic continuation of the process of analysis, presenting the findings in such a way that encourages the reader to be part of a shared experience which is about making sense of the participants' perspectives on and experience of respite care together as human beings. I am reminded here of Steedman's words (1991) that I have previously referred to as summing up my view of the world:

"It is worth noting here that, despite the intoxicating attraction of scientific positivism as the best or finest sort of knowledge, most of what we know is not, and never was, of this sort. Most of what we know, most of the knowing we do, is concerned with trying to make sense of what it is to be human and to be situated as we are".(p.58)

These words indicate an interpretive perspective in which the reader is encouraged to construct their own understandings of the findings of the study within the context of the human experience.

This is one of the reasons why the style of writing constructivist Grounded Theory is so important as although the generation of concepts and the development of theory require that individual experiences are raised to a more abstract and theoretical level, in order to be meaningful, the style of writing still needs to be “evocative of the experiences of the participants” (Mills et al, 2006, pg 12). This is not only about being true to the interpretive paradigm in which I have carried out this study, it is also about recognising that as a professional doctorate, there are two products expected of the research (Yam, 2005). One of the products is an academic one in that I am developing a theory about respite care. The other one is about practice in which I need to be able to demonstrate how services were improved as a result of the study and how they can improve. It is therefore imperative that this study has meaning for clinicians and nurses in particular, who have a unique role to play in improving the experience of palliative care service users and carers.

## **6.2 Theoretical concepts**

In Chapter 5, I developed a diagram (Fig 5.25) which showed the theoretical integration of concepts within the need for respite care as I perceived it through the analysis journey. It offers the potential to provide us with a platform from which categories and concepts and the relationships between them can be understood, and a meaningful theory developed. One could describe this as a theoretical rendering of the process of analysis which encourages us to remain open to theoretical possibilities rather than coming to an abrupt end as analysis is completed. Charmaz (2006, pg 137) describes this as maintaining “analytic momentum” and as such, the findings are an interpretation that offer a fresh understanding of respite care within a framework of the perspectives, needs and

experiences of palliative care service users and carers which has the potential to be meaningful to clinicians and nurses. Findings from the study are reported through the concepts that emerged from the data all of which need to be considered within the context of the relationship between the service user and carer. These are:

- needs and acceptance
- choice and risk
- loss and gains

These concepts emerge from and relate to the major concepts which emerged in the study of

- vulnerability and resilience

Reporting the findings through the concepts that emerged rather than through descriptions of experiences is in keeping with Grounded Theory. Through the process of Grounded Theory analysis, we are able to “fracture the data” in open coding. We then need to “put it back together again in a more abstract and conceptual theoretical form” (Mills et al, 2006, pg 12) so that fresh light can be shed on the subject and meaning can be found in the data. Within this however, the challenge remains to ensure that the voice of the participants is central and that their different truths are reflected in the writing. Each of these ‘pairs’ of concepts indicate that the findings have both a positive and negative aspect, all of which will be unpacked within this discussion. It is significant and probably surprising to find that such concepts have emerged from research about a subject which I found to be under researched and generally spoken of in a trite and simplistic way. So this in itself is important as it demonstrates that the need for and

experience of respite care is complex and inextricably linked to fundamental human experiences such as 'caring' and 'being cared for' and within those experiences, 'feeling loss' and 'being isolated' or alternatively 'being found' and 'feeling included'.

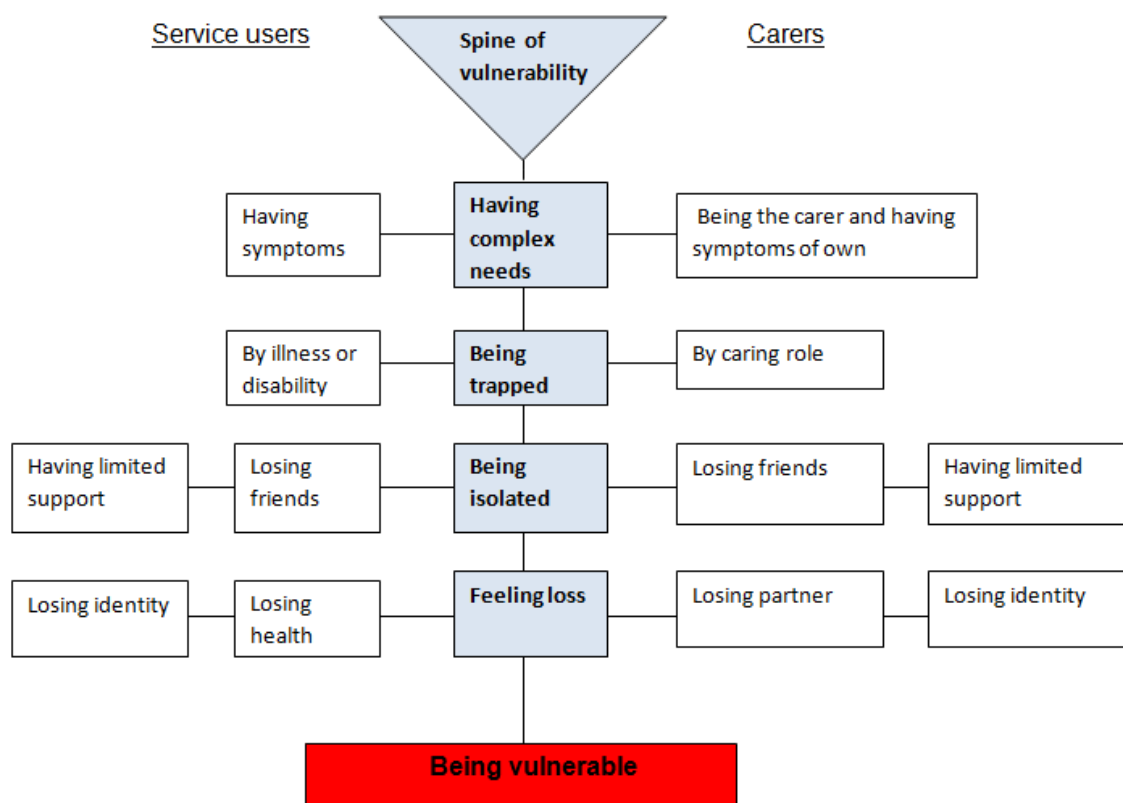
### **6.3 Vulnerability and Resilience**

#### **'Being vulnerable'**

'Being vulnerable' emerged from the data as the central category in the study. I would argue that there is much to be gained from using this as a starting point for our exploration of the findings from the study. One reason is that from an analytical perspective, it immediately engages the reader in a fundamental concern for the participants that is based on a shared understanding of the experience of feeling vulnerable and feelings associated with being vulnerable. Secondly, although the participants all showed, to a greater or lesser extent, an underlying resilience in that they were all surviving from day to day under extraordinarily difficult circumstances, there was what I found myself thinking of as 'a spine of vulnerability' which ran right through the experiences and perspectives of both service users and carers. I have presented this as a diagram (Fig. 6.1) below. The diagram emphasises the central position of the relationship in the study and how the relationship has to be central to any discussion about respite care because as one carer reminded me when I asked him what his idea of ideal respite care would be for him, he quite rightly said "Of course, there are two people involved here" (Dc1(viii) line 280). The diagram also confirms that in discussing respite care, the needs of the carer cannot be looked at in isolation from the needs of the service user and vice versa. Therefore, as well as providing a visual representation of vulnerability within the relationship between service users who have palliative care

needs and their carers, it makes clear that the experiences of both are linked together within the relationship:

Fig. 6. 1 A spine of vulnerability



The spine runs between the carer and the cared for person and the experiences of both are often shared and characterised by categories in the spine itself which emerged during analysis. For example, the category of 'being trapped' is shared by both service users and carers but they each experience it and express it in different ways. Linda explains how she feels that both she and her husband experience 'being trapped':

..."and it is quite stressful when you are confined with somebody, because you do feel as though you are confined. You feel a bit trapped, and I am sure he feels just as trapped really; he's trapped by his illness and I am trapped by him having the illness I

suppose...But the illness is the thing that's trapping us both" (Lc1(i) lines 795-801).

And Linda's husband confirms this by saying that he is "like a prisoner" (Gp3(xiii) line 85) adding to this:

" what I miss at the moment, all the health things aside, is my ability not really to be able to leave this place" (Gp3(xiii) lines 119-121)

This service user explains how she's becoming increasingly restricted by her deteriorating health:

Nora : "I can't do anything at all, and that's what makes me upset. I get really really screwed up about being like this, because I want to do what I want to do, not to be restricted.

Anna : yeah

Nora : But erm, obviously I am restricted, it's got to where as now, I can't get to toilet very well. I can go on a commode but, yeah that's fine but it's not very clever. But to go to toilet is getting a struggle. Getting downstairs is, I mean alright I've got the stair lift, but it's still a struggle to even get to there, even though I get wheeled there, my strength, what you say, whatever it is, I don't know." (Np1(viii) lines 14-26).

As Nora becomes increasingly restricted, so does her carer. Dick explains that he too feels "trapped" – "I don't have a life, I'm just basically in a cage. I'm trapped in a cage, the proverbial goldfish bowl" (Dc1(vii) lines 705-706). The degree to which participants experienced the different aspects of 'being vulnerable' varied but what is important is that the spine of vulnerability diagram (Fig.6.1) above is an interpretation of the data which is constructed in such a way as to indicate the fragility of the caring relationship and of both of the people within it. It provides the basis of a view of the different worlds that service users and carers may be occupying and in turn, how an intervention where the intention is usually limited to letting the carer have a break from their caring role – although very important in itself – goes no way to addressing the weaknesses inherent in the spine and the

potential for cracks and fracture should it be put under any extra pressure. The expressed need for respite care emerges from the experience of service users and carers as illustrated in the spine of vulnerability. As the diagram illustrates, at this time service users and carers are experiencing multiple losses and their needs are complex. The caring relationship is under significant stress and yet getting appropriate support is frequently perceived as what I've coded as 'being a battle'. Mary explained how being assessed for social services day care was a confusing and stressful experience:

"we're not spared anything; we're not spared anything and nothing is considered, that it might upset you or nothing. You are not protected in anyway. You're open to it all, there is no one to speak for you and say, 'hold on we've a carer here' you know?" (Mc1(v) Lines 87-91)

And many mistakes were made which added to the stress of caring:

"So once again the carer has to go into that and I had to ring up and I had to sit and I had to write letters and I started writing letters, writing letters, writing letters. That was my life. As soon as Ron had gone to bed, when I was dog tired, I was writing letters, and so it continued to be a mess, a holy mess". (Mc1(v) cont. Lines 122-126)

In addition, because of the complexity of her husband's condition, places that might have been acceptable for him to have residential respite care would not accept him. Mary spoke about how distressing this was for both of them and the pressure of trying to hide how worried she was from her husband:

"I used to sit in the loo and cry, sit in the bath, early hours of the morning crying, that's how I got rid of it without him looking on, because I felt he'd enough with his own disease than to see me in a state over things - the trouble I've had with the authorities, the trouble I've had with nursing homes. So I got to the stage when (pause) I said to my doctor 'where do I send him?'" (Mc1(v) Lines 623-628)

I use Mary's words to illustrate how fragile the caring relationship is and that there's little evidence to show that authorities have any understanding of this fragility and often how despairing people can become. With all of this in mind, I asked Mary whether she'd ever thought of Ron having to go into permanent



residential care and her words were very telling: “It did cross my mind, and it was also on the lips of the doctor” (Mc1(v) line 725). And so, the cracks in the spine start to show – not only because of the pressures within but from outside as well.

The fragility around and within the spine is particularly emphasised when respite care is needed in an emergency situation. There is nothing to support the spine when something unexpected happens and the pressure on carers to keep well in spite of their own health problems is enormous:

Dick: “And so you are just on a knife edge all the time, yep yep you are on a knife edge all the time.... and of course the other thing is if anything happened to me, if I became, you know, we’re in stuck. And that’s the other thing you know, I’ve got to keep reasonably

Anna: you’ve got to keep well?

Dick: Yeah”. (Dc1(viii) lines 222-238)

We know from the experiences of Linda and Geoff described in Chapter 5 that the experience of emergency respite care can lead to many more losses being experienced including ‘losing protection’, ‘losing choice’ and ‘losing control’ for the service user but the carer also suffers losses as well. They too are ‘losing choice’ and ‘losing control’ and the cared for person loses protection as the carer loses their role as carer and protector. In the absence of respite care that is knowledgeable and open to learning from the service user and carer, the service user is put at risk and his or her vulnerability increased.

‘Being vulnerable’ is often where the need for respite care is expressed. The red colour in the spine of vulnerability diagram (Fig.6.1) denotes the depth of feeling and the intensity of feelings that are properties of that category and it is from that category that I illustrated the theoretical integration of concepts in the need for

respite care as experienced by the participants in the study (see Fig 5. 25). 'Feeling ambivalent' about respite care was noted to be part of this experience but the extent to which there was ambivalence was directly related to what extent the care setting was trusted and whether the carer felt the staff had the knowledge to care for the person they cared for. There is less likelihood of ambivalence if the setting is trusted and it is believed the staff have the knowledge.

Within the context of the need for respite care, I found that the relationship between the service user and carer was not protected. This is not to say that respite care hasn't got the potential to offer a protective factor in that respite care was felt to be something that was needed in order for the carer to carry on caring. However, if respite care did protect the relationship, it was by default only and indeed there was evidence that sometimes, respite care was helpful to the service user but not for the carer. This was related to 'being apart' which I developed as a category. In 'being apart' which is for the most part inherent in the experience of 'having respite care', the vulnerability of the relationship is exposed as there are risks involved for both service user and carer particularly if the setting where respite care is taking place is not trusted and both the service user and carer can experience 'being at risk' in their own respective ways. But there are also risks involved in simply 'being apart' if the intervention is focussed only on one person. This was evidenced in the fact that the service user gets an opportunity for 'building relationships' in a good respite care setting while the carer's experience is about 'having a rest'. There is a sort of neutral value to the carer in this case which can lead to feelings of 'being left out' or 'not included'. This then shows how even when the experience of respite care is positive for the service user, there is the potential for the relationship to be unbalanced by an intervention that is supposed to be helping to sustain the relationship.

It was through the use of memos that the concepts associated with a 'one size fits all approach to respite care' were developed and in turn underpinned by the major concept of vulnerability. The findings related to these concepts are reported on under their respective headings but they are all related to and developed from the concept of vulnerability.

### **'Being resilient'**

While I have used 'being vulnerable' as a starting point for our exploration of the findings from the study for the reasons I have explained, the findings show that palliative care service users and carers do have resilient qualities that have the potential to be strengthened with the right sort of approach to their care and support. In this case, the spine of vulnerability diagram (Fig.6.1) remains appropriate because as well as it being symbolic of the fragility of the caring relationship which can be cracked and fractured when put under stress, the spine is also a symbol of strength. We talk of the importance of 'having back bone' as meaning 'having strength' and as such, the spine is capable of being strengthened. This diagram therefore captures the vulnerability of the world of palliative care service users and carers but it also captures an inherent strength or resilience within the spine and the potential for it to be strengthened with the right care and support. I have used the term 'being resilient' as the opposite to 'being vulnerable' as opposed to simply 'being strong', because I believe the term resilience captures better the sense of strength in adversity; being able to bounce back in the first instance (Bluglass, 2007) and more than that, a sense of adaptability and potential for growth (Monroe and Oliviere, 2007). The quality of 'being resilient' was more evident in some participants than others. Anita told me about how capable she had felt caring for her husband

Anita: but err, yeah it was hard and how I did it? –well, I do know because that's who I am, I am very capable and when he was in hospital they couldn't cope as well as I could. And that's not me being big headed

Anna: no, no

Anita: I knew exactly because I grew with it. I taught myself different ways, erm

Anna: to manage different things?

Anita: to manage, different things, and each phase of the Parkinson's, I found a way round it or we found a way together. (Ac1(vi) lines 223-232)

I underlined the last sentence while coding because it highlighted the carer's resilience but it also tells us that Anita's husband contributed to this process of 'finding a way around things'. We could interpret this as finding resilience in 'being together'.

One service user and carer wanted to be interviewed together. Greta explained to me that she had a number of advanced life limiting conditions including cancer, but that she was "still getting through everything...in there fighting with Steve's (her husband's) help" (S&Gcp1(vii) Lines 11-12). There were other 'being resilient' factors noticeable in this relationship like humour about her situation. Greta told me about being able to have beauty treatments at a respite centre for people with MS "but I don't go for that now because she (the therapist) doesn't give me half price for half a face!" (Line 42). I was a bit taken aback by this and not sure quite how to respond, but Greta reassured me smiling "that's my joke I have with her" (Line 45). Greta was referring to the facial surgery she had had to treat her cancer. She and Steve also shared a joke. I was asking Steve whether he saw any disadvantages to Greta going away for respite care – "yes" he said- "she comes back" (Line 926). I laughed and then suddenly thought maybe I shouldn't have laughed - "that was a joke wasn't it?" I asked anxiously, and they both laughed.

There was quite a lot of laughter in these interviews and Steve was unusual in the study in that when I asked him if he found caring for Greta rewarding, he said he did:

Steve: Yeah, when you've known somebody for as long as I've known her like, you know everything about them don't you? *(laughter)* You know we got together as kids like and that's what it is.

Anna: And so, Steve would you say for you.... there is a rewarding element to caring for Greta?

Steve: Oh yeah, yeah, because you know you're looking after a person erm and you can see how they are if they are finding they can do things any easier, then it's because maybe you've helped them.

Anna: mm, mm

Steve: That's about all you can do really (S&Gcp2(xvi) Lines 264-276)

However, he still acknowledged that it was hard and he could understand why others might not be able to cope:

"You either get on with it and don't like it or you take the back door, and we know a lot of people that's done it. We knew a bloke that worked for the fire service, and he just walked out and left his wife, and a lot of people called hell out of him but, you know, over the years you can actually see why. That's why I don't complain with anybody who can't hack it and just goes, because everybody isn't built that way".(S&Gcp1(vii) Lines 783-790)

Steve's words acknowledge, without making any judgements, that everyone is different and I interpret what he says as demonstrating that not everyone is the same when it comes to 'being resilient' as he appears to be in his relationship with Greta – "everybody isn't built that way". This led me to reflect on the elusive qualities of 'being resilient' and how 'being resilient' appears to be fundamental to sustaining a caring relationship. Can respite care therefore have any part in promoting resilience in the caring relationship?

Through the writing of memos in the process of analysis, I was able to lift the positive categories associated with a good experience of respite care into a major concept of resilience which in turn underpinned the positive concepts relating to and from 'a palliative care approach' to respite care. This process is shown in the theoretical integration of concepts in the need for respite care diagram (Fig 5.25) at the end of Chapter 5.

In developing the major concepts of vulnerability and resilience underpinning a 'one size fits all' approach to respite care and a palliative care approach to respite care respectively, I was able to unpack the concepts to which they related to and from in order to demonstrate that there is nothing straightforward about respite care. What was clear was that if any type of respite care has the potential to promote resilience in palliative care service users and carers, it is associated with a palliative care approach which is valued by service users and carers.

#### **6.4 Needs and acceptance**

##### **'Needs not being met'**

The need for respite care has been clearly established in the study and it is clear that this need is based on a deficit model in which service users and carers experience 'being vulnerable' and in which support is limited and the structures underpinning that support are often confusing and stressful. The negative experience of 'needs not being met' is associated with a 'one size fits all' approach to respite care which is characterized by the carer 'not being listened to' and the service user 'being put at risk' through 'staff not having the knowledge'. I would argue that this stems from the notion that any organisation can provide respite care because, the cared for person is cared for at home and therefore his or her

needs cannot be complex enough to warrant skilled care. Respite care is perceived as low skill work. Mary recognises that respite care isn't straightforward:

Mary: "It is difficult –'respite', I think is a very difficult, erm what's the word erm 'package' to offer people I think to give respite care; when you think of all the different people with all the different diseases.

Anna: mm

Mary: It is a very hard job" (Mc1(v) Lines 173-178)

### **'Needs being met'**

Alternatively, the experience of 'needs being met' enhances the development of accepting support, in the form of respite care, by the service user and carer. For the participants, this was associated with a palliative care approach or participants 'preferring hospice care'.

'Needs being met' was particularly evident in the participants' experience of hospice respite day care which to some of the participants emerged as more important than in patient respite care. It was even described by one service user as being the "the key to the rest of the world"(Gp3(xiii)SNC3). I underlined this because I found it a very powerful statement particularly bearing in mind the feelings expressed by service users of 'being restricted', 'being trapped' or 'being like a prisoner'. Hospice respite day care appears to directly address this by offering a "key" to the way out and beyond!. It was associated with a significant number of positive categories which participants identified with as follows: for the service user : 'having a purpose', 'building relationships', 'having choice', and 'sustaining the marital relationship' and for the carer: 'being a relief', "a little bit of freedom", "knowing he's happy", and "we're both benefitting". While the experience wasn't without drawbacks – for the service user, there is the issue that at a

hospice, people you build relationships with are likely to die. For the carer, there was the feeling of 'being left out' as the service user builds relationships while they don't get that opportunity. This reinforces that respite care has to be about meeting the needs of two people if it is to be truly beneficial to both parties and in turn, if it is to promote resilience.

For some participants though, as the service user's health deteriorated and their needs increased, hospice day care was not as helpful as it once had been. Dick explains why:

Dick:" Like I say without going into all the details, I'm up crawling around this house all hours, erm but I probably go up about 7am thereabouts to half past 7 to get her breakfast, sort her out with the tablets, sort her out with everything she wants, give her a bit of a wash, get her clothes out, get her dressed, get her in the car which is an absolute nightmare. Get down to The Oaks, get her in to The Oaks, get her settled in The Oaks and come home, stop off for a paper and by the time I get back here it's 11 o'clock.

Anna: Yeah.

Dick: Get myself a cup of coffee, read the print off the paper and by quarter to 2 I'm on my way back again,

Anna: mm

Dick: And then, when I get her out of The Oaks, I have the same procedure, where I've got to get her in the house, get her upstairs, get her clothes off, get her night-clothes on, get her sorted. And then it is 4, half past 4 ish, 5 o'clock, and then I start thinking about getting some tea ready. So it's probably a good thing as far as Lily's concerned, although it's really becoming an effort to her

Anna: yeah

Dick: but as far as I'm concerned, yeah I suppose it gives me an hour, out of

Anna: out of a day?

Dick: out of 5, yeah. (Dc1(viii) lines 361-386)



For Dick, his only hope of a rest from his caring role came in the form of inpatient respite care at The Oaks Hospice. This was the only place that his wife would agree to go to and therefore the only place that was acceptable to them both and the only place that met their needs. 'Preferring hospice care' was a memo which generated concepts concerning needs, protection, acceptance and choice (see Chapter 5, section 5.11).

### **'Being accepted'**

"...because it was so beautiful -and the ethos there - and he was treated like a human being." (Ac1(vi)Lines 293-294) 'Being accepted' was associated with 'needs being met' and 'preferring hospice care'. The sense of being accepted flows through the words that service users and carers used to describe the experience of hospice care or 'receiving a palliative care approach'. I would describe these codes as 'falling out' of my analysis of the data and coming back together through a memo (see Chapter 5, section 5.11) to this lovely shape which I believe is symbolic of a sense of peace, balance and acceptance:

Staff having time  
Staff having expertise  
Taking suffering into consideration  
Being more understanding  
Being cuddled  
Being so cared for  
Being allowed to do things  
Being allowed to be a person  
Being spoken to as a person  
Being treated like a human being

Rather than these words being limited to being about a certain place, I prefer to interpret them as being rather about “an ethos” and as such, feelings that could potentially be experienced in other settings or within other relationships, if a palliative care approach was adopted. ‘Being accepted’ though is a feeling that is dependent on having a relationship with the person who is caring for you and it is an apparent reluctance to engage in a relationship which seems to characterise the less positive experiences of the participants in the study. Nora explains that at the hospice, “they are caring – come and give you a cuddle, you know? .... To me that’s marvellous” she says and she goes on to explain that she hasn’t experienced that sort of care in hospital:

“You don’t. Oh no you don’t coz I don’t like the nurses, some of them, some of them are alright, some of them are fine. I get on with the majority because I’m easy come easy go, and I get on pretty much good with everybody but there’s just that element of people you know, a couple what think they’re on their high horse and they don’t want to be doing this for you and doing .....If you ring your bell you wait ½ hour and this one scenario I had with one nurse, I mean I can’t do anything for myself, nothing, and she said to me - oh I said I wanted to go to toilet, so she said ‘right we’ll get you to toilet and then you can get yourself washed’. I said ‘what?’ she said ‘get yourself washed’ I said ‘yeah alright then’ so they took me to toilet, brought me my washing gear, I just looked at the water and said ‘I’ve done it’ and that was it. You know I couldn’t do it and that was you know that was a bit bad.” (Np1(viii) Lines 170-186)

One could interpret the nurses’ behaviour in this situation as trying to encourage Nora to be more independent which maybe said to be laudable, but what we sense from Nora’s recollection is that she didn’t feel that the nurse had any empathy for her. The nurse does not carry out her instructions to Nora in the context of a relationship that is empathic and accepting and in turn, Nora responds to the nurse in what I would interpret as almost a defiant manner. Most importantly, Nora experiences a poor outcome to the nurse’s intervention.

Another service user, Geoff, told me that he wasn't impressed with the staff and volunteers at NH2 where he went for respite care. "Why didn't they impress you?" I asked, "I don't know really" he replied, "just got the impression that they were scurrying away" (Gp2(iii) Lines 66-67). I was intrigued by Geoff's use of the phrase "scurrying away" and I interpreted this as capturing that sense of staff being actively reluctant to be involved with him in the same way as the nurses were with Nora as described above. "Being accepted" can't happen if the nurses are "scurrying away". As such, I found that 'being accepted' was a core outcome of a palliative care approach that is characterised by a willingness to engage in an empathic relationship with the service user and carer and I would agree with Simon et al (2009) that this attitude could be described as "mindfulness". My findings showed then that where there was mindfulness within a palliative care approach, service users and carers had a positive experience of respite care and experienced 'being accepted'.

## **6.5 Choice and risk**

### **'Having choice'**

"What does it do for me? Gives me a bit more responsibility again. Going on a Friday to The Oaks, tend to congregate in the same areas, 'you can sit wherever you want' they said that when they offered, you can sit where you want, do what you want". (Gp1(ii) lines 361-365)

Service user Geoff tells me what he likes about his weekly day care at The Oaks. 'Having choice' is directly related to 'being accepted' and 'being allowed' which both emerge from and relate to a palliative care approach. The diagram below (Fig.6.2) uses growing circles to depict the sense of capacity for growth and development within a framework of care where acceptance and appreciation of the service user in their being is embraced. It acknowledges this acceptance and

appreciation or 'mindfulness' as described by Simon et al (2009) which leads to 'being allowed', as a core quality of a palliative care approach.

Fig.6.2 Circles of acceptability in respite care



Mary talks of the hospice as a place where Ron “was allowed to do certain things.....where he was allowed to be a person” (Mc1(v) Lines 302-304) and another carer explains “the ethos” of the hospice in terms of her husband being able to “you know, read the books and sort of wander around” (Ac1(vi) line 354). The artistic language Geoff uses to describe how he was able to draw and paint in the garden at the hospice “in a white straw hat like Monet” (Gp2(ii) line 389) evoke a sense of sunshine and freedom and of ‘being allowed’:

“Well I didn’t take the easel at that point, you know I had a drawing board equivalent and I found that I could go and actually draw a lot of examples of things that I could draw quite easily but it didn’t look like anything. So I thought this is an abstract concentration of ideas and houses and colour and atmosphere, textures of the ground, water erm goldfish and carp and everything else all at your disposal really there”. (Gp1(ii) lines 393-400).

'Being allowed' is highly valued by service users and carers in their experience of respite care and it is a quality that enhances the acceptability of respite care for them. Thus, I have referred to the diagram above (Fig.6.2) as 'Circles of acceptability in respite care'. I have used different colours in the diagram to ensure that it is not confused with earlier circle concept map diagrams that were generally depicted in blue but I have also used different colours as a reflection of the holistic nature of a palliative care approach. I also wanted the colours of the diagram to capture the warmth and colour of Geoff's description of his experience of hospice respite care as shown above.

## **Risk**

### **'Staff avoiding risk'**

In the study, I found the concept of risk to be fundamental in developing the theory that respite care is not straightforward. In developing the concept of risk in opposition to choice or enablement, the first interpretation exposes poor practice in the provision of respite care as experienced by the participants in the form of staff avoiding risks and in turn, service users not being able to experience 'being allowed'. This was very frustrating for service users and carers who commented on it and it could be distressing. On the whole, Anita was very impressed with ambulance drivers who transported Tom to and from respite care or hospital. However, there were some exceptions and Anita explained how she had to "fight hard" for ambulance staff not to be what she perceived as over cautious in their management of Tom's disabilities:

"And I really fought hard for him because there were a couple of ambulance drivers that insisted, at one point that he laid down in the thing. And I remember him coming home and he was sulking, and I said 'what's the matter? what's happened at The Oaks?' 'Nothing' so I said 'what's the matter Tom?' 'Oh they made me lay down in the

van' and I said 'who made you lay down?' and they said 'oh well we can't be bringing him home like that'. So I said 'like what? 'Well he'll be falling' and I said 'no he won't and he certainly doesn't want to be laid down'. (Ac1(vi) lines 790-797)

Anita describes this and other scenarios as a fight to maintain Tom's independence and dignity which I was particularly interested to hear about because in the interview immediately prior to this, Mary explained how her husband Ron was seen as "a liability" because he was at risk of falling. In the social network circles exercise, Mary explained that Ron was told "you are a liability- no one will take risks with bathing and falling" and her experience often confirmed this. In the following extract, I am trying to understand and make sense of Mary's experience which was very distressing for her:

Mary: "And it was a nursing home but they were going to have him for the day, and they took so many day people for days. And it was a corner of heaven, with the garden and facilities, the cleanliness, everything was ideal; and he went for the day and he was completely happy, they gave him a shower and they helped him. When I went for the report, they couldn't have him anymore and I was so shattered because I was even willing to take him because it wasn't all that far away, you see, it was in the area.

Anna: yeah

Mary: And I thought I would go in my own car, take him

Anna: yeah

Mary: because he fell out of his wheelchair, so that was it. And when he came home he was almost in tears when I had to announce 'you're not going here' he (pause) it was lovely and they made a fuss of him and 'oh he's lovely'

Anna: so why...?

Mary: 'bye Ron, see you again!' Oh he is lovely, and oh.... and it never happened anymore.

Anna: But why - what was the problem?

Mary: I was shocked. I just was absolutely so shocked, I was days in shock.

Anna: Why?

Mary: Because he was a liability” (Mc1(v) lines 540-560).

I found that the category of ‘staff avoiding risks’ was linked with the category of ‘not being listened to’ because it seemed to stem from ‘not having the knowledge’ of the cared for person. What appears to be missing is the willingness to accept that the carer has knowledge that can help them manage the cared for person in such a way as to minimise risks and improve the outcome of the care they are giving. The following extract is an example of this:

Anita: “And they said ‘how can we get him in the house?’ I said ‘he’ll walk in’. ‘Oh he can’t walk in’. So I said ‘oh he can’... I said ‘he’s got Parkinson’s disease, but if you rock him, you know....I said ‘there is no need for him to have a wheelchair at the ambulance’.

A: mm

Anita: Just need to do this and he’ll walk. And he did do right to the very end, but there were a couple of ambulance drivers, one in particular, but all the other ambulance drivers put up a fight for Tom, and won in the end” (Ac1(vi) lines 803-814).

This reinforced to me how the best respite care interventions have to include a willingness to listen to the carer, empathise with the cared for person and establish a relationship with both that is based on working together and learning from each other.

### **‘Being at risk’**

“I think you should be treated with respect, and be given the care; you don’t want to be coming out of somewhere worse off than you went in”. (S&Gcp 1(vii) lines 830-832)

“But it needs, I suppose to be a continuation of what he’s been doing at home, if possible.....If he has a therapy of some kind that is listed, then to continue with that would be a help, so that there isn’t break from everything. So that when he comes home he won’t have just been sitting and his ankles all swollen, that happened once you see”. (Mc1(v) lines 278-284)

Although analysis showed that staff in certain areas were showing risk avoidance behaviour, the experience of service users being put at risk while experiencing a one size fits all type of respite care was a common theme. 'Having choice' and 'being allowed' was limited because of the availability of acceptable respite care to participants and analysis of the data showed was that this was particularly the case where respite care has to be found in an emergency as described earlier in this chapter. The wellbeing of the cared for person being put at risk is probably what worries carers most about accepting respite care and it is a concern to both the carer and cared for person. Anita told me how important it was for staff who are providing respite care to have a knowledge of Parkinsons Disease:

"No, in hospital or anywhere people are so uneducated about Parkinson's Disease, they know nothing. It was traumatic some of the time when I had to visit him in hospital, they didn't give him his medication on time, they over injected him with Apomorphine where it was, oh it was awful. Erm he had his own, I understand that they have rules, but I've had a tough time on some of the wards even though the Parkinson's nurse has been there when I've gone to visit; Tom has been crying, he's been overmedicated and hallucinated and I've said "what's the matter with him?" and he's tried to tell me, "I haven't had my 9 o'clock pills" and it's the afternoon, and I've spoken to them and they've said "oh well we are too busy" and I've said "he's got to have his medication on time." (Ac2(xv) lines 110-123)

An approach that grows out of mindfulness into circles of acceptability (see Fig. 6. 2 above) can be compared to an approach which descends into the service user being at risk. This diagram is symbolic of a lack of potential for knowledge development and exchange in which the complex symptoms of the cared for person and the knowledge of the carer are implicitly denied and the expectation is that care can be provided within a framework of low skill:



Fig 6. 3 A descent into risk



This approach is associated with respite care that is not acceptable to service users and carers. However, they often find themselves having to accept it because they have no choice.

## 6.6 Loss and gains

The fact that service users and carers often have no choice but to accept respite care even when it is not acceptable brings us back to the spine of vulnerability (Fig. 6.1) and the many losses that are experienced by service users and carers as health deteriorates and the caring role becomes more challenging. As we have seen, the need for respite care develops from the experience of being vulnerable and the experience of loss is very much present within this process as it can be within the experience of respite care itself. Respite care appears to be

characterised by a mixture of losses and gains that vary depending on the person, the situation and the experience. Geoff's experience of respite care is typical of this dichotomy in that the inpatient respite care at the Oaks Hospice sounds to have had many positive outcomes for him as described above. However, when I asked him how he had felt when he returned home, he reinforced to me that however acceptable his experience of respite care was, he was "glad to be back home...you know, irrespective of what you've just been to, home is best....I'm always glad to be home" (Gp1(ii) lines 404-410). This reminds us that implicit in the experience of inpatient respite care particularly is that the service user has to come away from their home whether they want to or not so that the person who looks after them can have a rest. In addition the carer also experiences a loss of choice because they feel they have no alternative but to accept respite care as this is the only thing that they feel will help them. Analysis showed that this loss of choice can often mean service users have to be persuaded to accept respite care and sometimes, not always, even if the respite care is of an acceptable quality, the experience can leave the carer feeling guilty and sorry for the person they are caring for:

Linda:" Well I mean I suppose, I feel sorry for him because he's away from the home, and he's sort of forced into that position.

Anna: Yeah

Linda: Which is sad,

Anna: Yes

Linda: and I do feel sad for him over that." (Lc2(iv) lines 227-233)

And pleased when the person they care for is looking forward to coming home:

Anita: ..... And I would say (to Tom) don't ring me please. "why?" Well I don't really want to know what you are doing. I know you'll be ok, you know, don't ring because it will make me feel guilty that you are there, erm. But the very last time he was in and he rang and said, a couple of nights before, and he said I am looking forward to

coming home .....And I sort of remember that with pleasure really”.  
(Ac1(vi) lines 552-557)

There is no doubt that most of the losses service users and carers experienced in their experience of respite care were associated with a one size fits all approach and the ‘gains’ were more associated with a palliative care approach as I have demonstrated. It was within this approach that respite care was consistently described as being very important. As a bereaved carer, Anita felt she was suffering since her husband had died, in the sense that because she didn’t get enough support when she was caring for Tom, he became her whole life. She explained her feeling that if she had had more acceptable regular respite care, her bereavement would have been easier to cope with:

”...and that is why respite is so important because they die and there is just half a person left.

Anna: yes

Anita: And it is half a person. I mean I am a lot better than I was a year ago, erm but I didn’t know who I was, I didn’t know...” (Ac1(vi) lines 908-912)

Anita’s words make a very compelling personal case for the importance of the provision of respite care and the potential for ‘gains’ to be experienced. We have also seen that respite care can be experienced as mutually beneficial by both service users and carers. The data showed that there could be gains attached to respite care particularly if it was in day care delivered within a palliative care approach. However, the complex feelings associated with the experience of what Mary described as the ‘package’ of respite care are never far away. Even within a positive experience of respite care, there is still the potential for losses to be experienced and for the intervention to be of limited value. Nora told me how Dick was “a different person” when she first came home from respite care but that he soon went “back down again”(Np1(viii) lines 269-271) and as a carer, Anita

echoed this view when I asked her about whether she thought respite care had helped sustain her relationship with her husband:

Anita: "Yeah because I was always pleased to see him,

Anna: yes.

Anita: When he came back, and I think he was always pleased. So yes it did help, yeah it did help a bit. I thought, oh yeah it'll be nice to see him and it didn't last long, you know I mean?

Anna: yeah, yeah

Anita: I mean you got back into the gruelling you know thing again. But yes it did, undoubtedly and if I had had more it would have been even more beneficial. Just a little bit and often, you know." (Ac1(vi) lines 292-300)

For me, the analysis process unearthed these tensions – the losses and the gains, and the losses and the gains within the gains in the experience of respite care, became clear to me and as I present them now in my findings, the reader is invited to join with me in asking why these tensions exist even in the experience of acceptable respite care.

## **6.7 Capturing the emerging theory**

This is where Grounded Theory presents us with a unique opportunity to interpret what we have learned from the analysis together, and develop a shared understanding. I believe that the findings show that palliative care service users and carers do value respite care, particularly when it is provided within a palliative care approach, and it is important to them. However, there are a number of reasons why it is limited in its value:

- It is provided on a deficit model of social isolation and limited support.

- It is delivered as an end product in itself and it is not part of any sort of on-going process of support that is cogniscent of the long term needs of palliative care service users and carers.
- It is delivered within a context of mixed messages from society and in turn, providing organisations, which stems from its lack of definition and a lack of clarity about whose needs 'respite care' is supposed to meet and what it actually means. I believe this has a knock on effect to the way service users and carers feel about the experience of respite care and the importance providing organisations place on it.

On the one hand, society says that respite care is important for carers (DoH, 2008a) and yet our findings show that the availability of it is extremely limited and if it is available, it is either very expensive or the expectation is that it can be delivered within a framework of low skill where there is little potential for knowledge development and collaborative learning. This is the case even though the service user and carer separately and together have complex needs. Society's ambivalent attitude towards respite care is captured in a brief but extremely full sentence from Mary when she was telling me about her husband's experiences of respite care and how on one occasion:

"because it was respite, he was put in a very tiny room at the top of the place, which was very very hot", Mc1(v) 677-678.

I underlined this sentence as although I missed its significance to start with, I realise now that it is an identifying moment. Respite care is very important to Mary if she is going to be able to carry on caring and keep her husband at home. She has had to persuade her husband to have respite care because he is reluctant to leave his wife and home and she is reluctant to let him go. So the backdrop to this sentence is that there are big and even heartbreaking decisions behind Mary and

Ron getting to this very tiny hot room at the top of the building. And of course there is an absolutely clashing incongruence between where they find themselves and the heartache that has led them to be there. In my view, the message to Mary and Ron is deeply confusing because even before anything has been said, the picture tells the story – respite care is not our priority and your need for it is not understood or valued. I coded this sentence as ‘not being important’. While other participants may not have been put in a tiny hot room at the top of a building, they had all experienced standards of care that tell the same story as Mary’s picture. You are not important – anyone could provide this care. I would argue that this is one of the reasons why hospices continue to struggle with the appropriateness of providing respite care because it comes tagged with a low skill/low value label which is not perceived as worthy of specialist palliative care. When respite care is provided within a hospice setting though, for service users and carers, I believe it awards the need with a credibility and understanding that is helpful in itself. This is part of the reason why respite care service users and carers prefer hospice care as much as they do and it is within a palliative care approach that respite care is experienced most positively in spite of its inherent tensions.

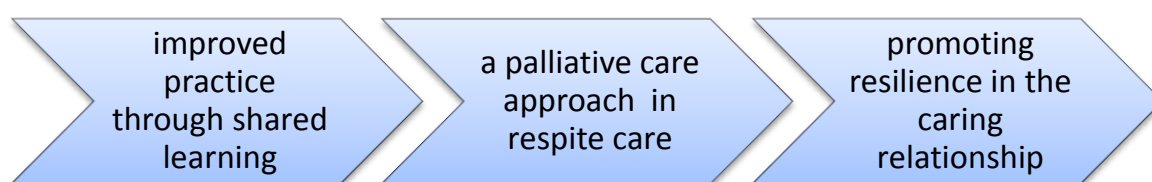
The following chapter gives us an opportunity to explore the findings further within the context of the existing literature and in so doing, identify the new knowledge that has emerged from the study. It will also show how the articulation of respite care needs and the insights gained in the study have the potential to influence practice and provide a platform for service development and improvement.

## Chapter 7 Integration and Discussion

### 7.1 Introduction

I begin this chapter with a proposed model that puts a palliative care approach at the centre of a new approach to respite care for palliative care service users and carers.

Fig. 7. 1 A model for promoting resilience in palliative care service users and carers



On the surface, the diagram appears to demonstrate a straightforward process. The study has shown that a palliative care approach to respite care is most likely to lead to the intervention sustaining the relationship and promoting resilience. This is because in a palliative care approach, the whole person is embraced and there is evidence to say that both service users and carers can benefit from it. Most importantly, because it is underpinned by improved practice coming about through integrating theoretical knowledge and practice experience, there is the potential for development of models that could promote resilience within the caring relationship. However, as previously described, the findings have also indicated some fundamental tensions which lay at the heart of the concept of respite care that require further exploration if we are to realise the full potential of this model and the role it could play in promoting resilience in the caring relationship. As such, Fig.7.1 (above) is a rather flat interpretation of the proposed model which requires further development. It is the identification of these tensions that add to the distinctiveness of the study and the unique contribution it makes to the existing

literature. The chapter will also demonstrate how the study has added to what have been identified as gaps in the palliative care literature about respite care as follows:

- That little is known about respite care for patients with life-limiting illnesses (Ingleton et al, 2003, Owen and Johnson, 2005, Skilbeck, 2005).
- That there is a lack of research to support the efficacy of respite care (McNally, 1999, Ingleton et al, 2003).
- That there is a problem with definition in respite care (Payne et al, 2004, Owen and Johnson, 2005, Satterley, 2007).
- That there needs to be a better understanding of the complex issues surrounding the expression of need and the acceptance of help in palliative care carers (Grande et al, 2009).
- That there is a lack of evidence on how best to address carers' needs in palliative care (Grande et al, 2009).

In order to demonstrate this, the discussion will be developed through the framework of the theoretical concepts that emerged from the study which are:

- needs and acceptance
- choice and risk
- loss and gains

These concepts emerge from and relate to the major concepts of

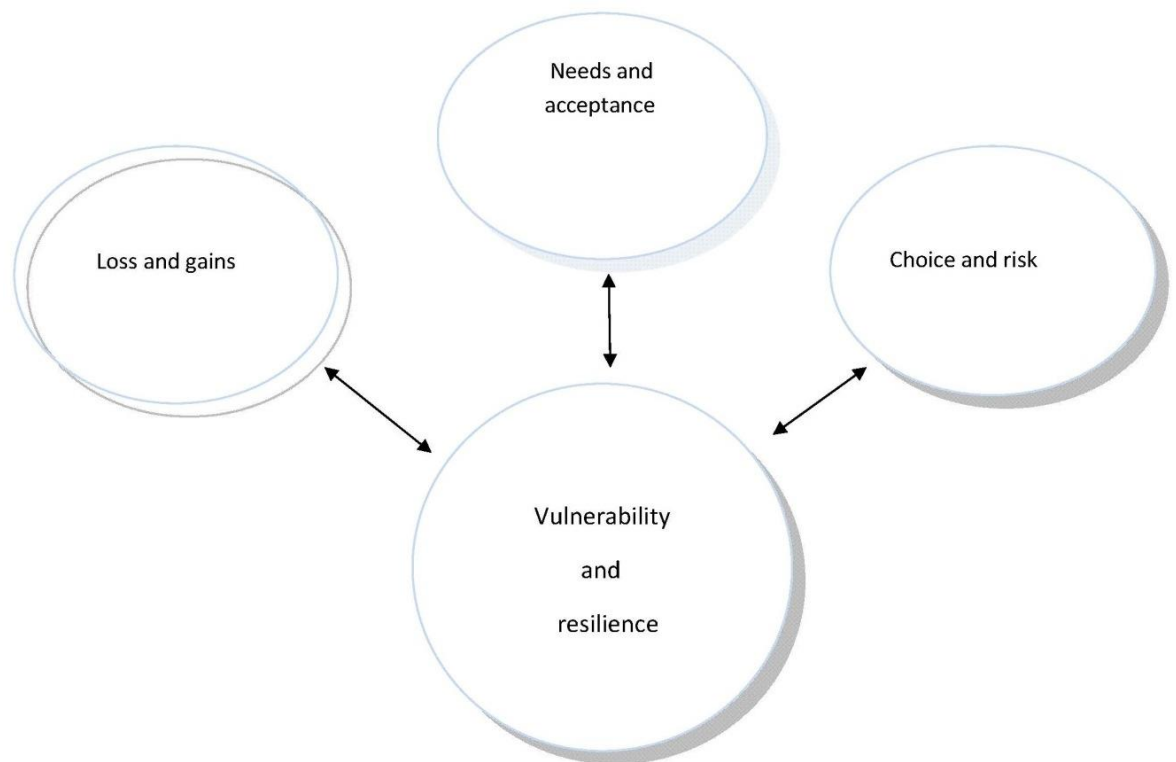
- vulnerability and resilience

It is through this framework that the theory I have developed can be seen to progress. Below, in Fig.7.2, I have presented the theoretical concepts as a conceptual map. Concept maps are used to organise and represent knowledge and in so doing, help the reader construct new meanings in the subject (Novak,



1991). The diagram is shaded in order to enhance the sense of the map as a lens through which the discussion of respite care is illuminated.

Fig. 7. 2 Conceptual map as a lens



Vulnerability and resilience are central in the diagram and the arrows show that the concepts of needs and acceptance, choice and risk and loss and gain, all emerge and relate to them.

I have used the term 'progress' in relation to theory development in the sense that a Constructivist Grounded Theory method can be described as a "discovery process" in which the researcher gains further insights and creates more ideas (Charmaz, 1990) at all stages of the journey. There is not then a finished product as such, as process is at the heart of the Grounded Theory method. Theories developed are always open to change and as Charmaz (1990 pg 1171) explains, they "cannot be frozen in time". I think it is this sense of process and discovery in

Grounded Theory that reinforces the sense of a shared journey between the researcher and the reader. As the researcher is continually open to the theoretical possibilities of what they have learned, so too is the reader and I believe this sense of both researcher and reader continuing to be open to theoretical possibilities in this way is reflected in the idea of the theoretical concepts from the study being shown as a lens through which we can all see and interpret. Therefore the developing theory remains fresh and open to interpretation and the outcome of the study is at one with the symbolic interactionist philosophy that underpins Grounded Theory and the theoretical underpinnings of the research itself.

## **7.2 Vulnerability, resilience and the centrality of the relationship**

A unique quality of the study is that vulnerability emerged as the central category and the findings were contextualised within a framework of vulnerability as shown in Fig 6.1 'A spine of vulnerability'. Carers needs and adverse effects of caregiving have been extensively researched (Grande et al, 2009) and the negative impact on almost every aspect of life for the carer have been documented (EAPC, 2009). Having said that, there are carers of non cancer service users who have not received the same level of interest (Barnes et al, 2006, Grande et al, 2009) and are considered to be under researched groups. These include carers of patients with neurodegenerative disorders (Kristjanson et al, 2005) and respiratory diseases (Cain et al, 2000) both of which are represented in the participants in this study. However, despite the substantial amount of family carer literature in palliative care, few pointers have been given to service providers about how to address the needs that carers are documented as having (Grande et al, 2009) and the literature has really only recently started to acknowledge the complexities of caring relationships in palliative care (EAPC, 2009, Hudson and Payne, 2009,

Kellahear, 2009) and the place respite care has, or has not, within supportive interventions.

Although little is known about respite care for people with life limiting illnesses (Owen and Johnson, 2005, Skilbeck et al, 2005), it has become associated with reinforcing the negative aspects of caring ie being temporarily relieved of the burden of caring (Payne, 2007) and the lack of literature to support its efficacy (McNally et al, 1999, Ingleton, 2003) has led to a view that services should maybe look to other ways of providing support that emphasise the resilient and resourceful qualities of carers that previous carer literature has failed to acknowledge (Payne, 2007). The study has shown that carers do have resilient qualities and that those qualities have the capacity to be strengthened with the right support. However, the study clearly identifies that carers are vulnerable in a number of ways and it also demonstrates that the needs of the carer cannot be removed from the needs of the person they are caring for who is also vulnerable. The carer and cared for person are therefore linked together within vulnerability as the spine of vulnerability indicates (Fig 6.1). Within this, it is the *relationship* between the carer and the cared for person which becomes the focus of our attention and should in turn become the focus of supportive interventions. If respite care could be seen in the context of supporting the relationship rather than relieving the carer of the burden of caring, would that help to shift respite care from the negative position it currently holds in the literature to something that could potentially promote resilience? And, in terms of practice, would it help to improve the outcomes of respite care by not solely focussing on one party's needs at the possible expense of the other? Wolkowski et al (2010) comment on this concept of care as solely focussing on the needs of one party which has been noted to be

common in care policy (Forbat, 2008) and runs the risk of contributing to the polarization of the carer and the cared for person.

I am aware of the negative connotations of the term 'vulnerability' (Hasler, 2004) but I believe that the study has shown that palliative carers and service users are vulnerable, that the relationship they are trying to maintain is vulnerable and that the relationship needs protection. My view is that by acknowledging vulnerability properly and by focussing support on the relationship rather than individuals, there is the best opportunity to strengthen the relationship and promote resilience.

The study identified that one of the most valued aspects of hospice respite care was day care and more than in any other type of respite care, participants commented on the mutually beneficial nature of it and how it had a positive effect on their relationship. The existing literature on respite day care for palliative care service users and carers is minimal but in a qualitative evaluation of the impact of palliative day care services in 2005, Low et al found that although carers interviewed felt that their quality of life was not good, they felt they did benefit from respite day care and that it was a major element in contributing to "a positive improvement to their quality of life" (Low et al, 2005). Service users interviewed also commented that it was beneficial in that it improved their own quality of life and that of their carer – "a double edged effect" (Low et al, 2005).

I think this focus on the mutually beneficial nature of the intervention is what starts to undermine the negative construct of respite care. By moving the focus of respite care interventions from purposes like giving the carer a break, to providing care that supports the relationship of the carer and the cared for person through being mutually beneficial, I would argue that this leads to a significant shift in how this type of care is perceived. A change in focus from the carer or the service user to

the relationship dispels notions of burden and relief and moves towards a notion of care that is much more in keeping with a modern public health approach that promotes healthy relationships. Even though the focus of recent family care literature is on the needs of the carer, it also promotes an approach where the relationship holds a more central position (Ellis-Hill and Payne, 2001). Nolan et al (2001) promote the concept of relationship centred care which acknowledges the centrality of relationships in contemporary healthcare and their importance in determining our quality of life. Within this, the pivotal role of family carers is to be acknowledged (Nolan et al, 2001). Monroe and Oliviere (2009) recommend a systems approach to working with families in palliative care, Hudson and Payne (2009) favour a family carer oriented approach and Kellahear, (2009) promotes a public health approach in which both family and community relationships are strengthened. However, within this, respite care is generally reported on as being helpful (Kellahear, 2009) but stuck in a “reactive, ‘repair’” approach (Grande et al, 2009) with little to recommend it in terms of strengthening capacity and promoting resilience (Payne, 2007). This is the point where we need to explore further some of the tensions at the root of respite care which even when it is provided in the best possible way, the positive outcomes are limited.

### **7.3 Definitions, words and language**

This problem is multi-layered and I would argue it is at the root of the ambivalence organisations have with providing respite care, service users and carers have in accessing and benefitting from it and society has in supporting and valuing those who need it. In mapping the key messages from the existing literature, Wolkowski et al (2010) identified that there is currently no clear criteria agreed for the purposes of respite services (Payne et al, 2004). Hospices have no clear definition

(Satterley, 2007) and although it is generally accepted that it is the carer who is intended to be the main beneficiary, this is not made clear in the literature (Ingleton et al, 2003). Interestingly, in writing about “family caregiving in the home” in palliative care, Stajduhar and Cohen (2009) recommend that because ‘respite care’ means different things to different people, the best approach to take is to allow carers “to define what respite care might mean for them” so that individual needs can be met (Stajduhar and Cohen, 2009, pg 162). There is no doubt that it does mean different things to different people (Strang et al, 2002, Harding and Higginson, 2003, Payne et al, 2004) and it is not surprising that people struggle with the definition because:

“There is no definition of respite care anywhere within social security legislation. In effect, respite care is covered by provisions which govern temporary absences from the home.” (The Law Centre [www.lawcentreni.org](http://www.lawcentreni.org) Accessed 17 March 2012)

Added to this, the problem of definition is not helped by the fact that the route of the term respite care is embedded in the language of negativity and suffering. The following are definitions of ‘respite’ from [www.dictionary.com](http://www.dictionary.com) firstly as a noun:

- “1. a delay or cessation for a time, especially of anything distressing or trying; an interval of relief : to toil without respite.
2. temporary suspension of the execution of a person condemned to death; reprieve”

And then as a verb:

- “3. to relieve temporarily, especially from anything distressing or trying; give an interval of relief from.
4. to grant delay in carrying out of (a punishment, obligation, etc.)” ([www.dictionary.com](http://www.dictionary.com) Accessed 17 March 2012.)

From a linguistic perspective then, there is something of the quality of an oxymoron about the term respite care which at best is meaningless and at worst holds only negative connotations concerning the experience of caring (a

punishment) and the status of the cared for person (trying and a cause of distress). One could argue that definitions are only language but there is also an argument to say that we can only think what our language allows us to think (Harden, 2000) and as such, I believe the language we use is important and in the case of respite care, it does have implications for the way it is provided and experienced.

To the detriment of respite care, the language used means that it is separated out from other caring interventions. It's often referred to just as 'respite' and as we know from the study, because it is *just* 'respite', expectations are low. There is nothing about the term respite care which suggests any sort of openness to knowledge which the study has identified as being a fundamental component of acceptable respite care where needs are met. It also limits the possibility of either the carer or the cared for person benefitting from interventions.

When I began my study, I had a gut feeling that respite care may have its roots in the discursive practices of healthcare as identified by Gillman et al (2000) in that respite care was symbolic of 'expert' professionals wading into caring relationships and taking over. Through the study, I have shifted my position somewhat in the sense that I have learned that palliative care service users and carers do value *acceptable* respite care and more than that, see it as crucial in supporting their relationships. However, the study has also shown that service users and carers experience poor care under the umbrella of a one size fits all model of respite care and within these experiences, I would argue that discursive practices are at work and service users are viewed as 'less than' other citizens (Hasler, 2004).

Added to this, carers have to submit themselves to a process of 'assessment' where, within the negative construct of respite care, the carer can only 'qualify' for this sort of support if they are judged to need it which in turn adds to a sense of the

need for respite care being based on an admission of not coping. Within this construct, the cared for person is perceived as a burden and the only outcome is the temporary relief for the carer of that burden. Not surprisingly, in such situations, the service user is often put at risk and the carer is left feeling worried and guilty.

I would argue that we would do well to consider how much the language of respite care plays a part in this process. I have used the term respite care in the study as it is currently the only accepted term for the type of care I am studying. However, I am aware of the profound limitations implicit in the term and I am struck by how, in palliative care, we seem to be reluctant to critique language used to describe aspects of care. This is not the case in other areas of health care such as psychiatry (Mohr, 1999), learning disabilities (Gillman et al, 2000) and disabilities (Hasler, 2004) where there is an understanding that language is power (Foucault, 1965) and that care needs to be taken when using language as it has implications for how people are treated.

#### **7.4 Power, knowledge and discursive practice**

As described above, service users with palliative care needs can be subject to discursive practices. As well as being directly related to what I would describe as the disparaging construct and associated language of respite care, I believe this is evidenced through the continued acceptance of a one size fits all approach to respite care. Through the coding of identifying moments and in vivo codes, and the development of memos, we have been able to enter the worlds of the service users and carers in the study to experience as far as we can the loss of control, choice and protection that characterises inpatient respite care particularly when it has to be found in an emergency and a one size fits all approach is all that is



available. Within processes such as these, there appears to be a denial of the complex needs of the service user and an unwillingness to acknowledge the expertise of the carer. Where there appears to be a lack of knowledge on the part of the staff to meet the needs of the service user, there is a sense that the professionals believe they know best. I found that this combination was always detrimental to the service users and carers in the study and a recent newspaper article reinforced to me that these experiences of respite care were not isolated to the participants in the study. Mike Craig, who had Pick's Disease, was a famous comedy writer who recently died of pneumonia following a period of respite care in a care home. Mike's wife returned from being away to find her husband in hospital suffering from dehydration. "I had told staff at the home that he didn't drink much and needed encouraging but they didn't listen" she said (Sunday Mail Newspaper, 3<sup>rd</sup> March, 2012).

Another example comes from an online conversation which was part of a recent Department of Health consultation on "creating a more diverse and responsive care market" in "The Caring for our Future Engagement":

"Let me give an example: One of our clients returns home from respite in a Nursing Home where she has developed pressures sores having entered the Home with clear skin....."

The reply:

"...Strange sort of respite which ends up with the person's skin worse off than when they went in. Perhaps that's a story for another day?"  
<http://caringforourfuture.dh.gov.uk/2011/09/15/care-market>

Concerns about the quality of respite care provided in care homes for people with palliative care needs (neurological disorders) is documented in the literature (Cheung and Hocking, 2004, Dawson et al, 2004) and Owen and Johnson (2005) feel that respite care patients at their hospice have complex needs that could not

be met in the majority of nursing homes. Clearly my study and the literature questions the ability of care homes to provide the standard of care necessary to meet the needs of palliative care respite service users but I think what my study adds is the understanding that these failures in care are not primarily the fault of care homes but are to do with broader issues of trying to fit people with multiple and complex conditions into a one size fits all approach to respite care that is not adequate.

I would argue that this is rooted in the problem with definition in respite care, a discursive denial of the complex needs of the service user and an unwillingness to acknowledge that the carer has an understanding of the needs of the service user that they have not. This comes about through a belief that if the cared for person is cared for at home by a carer then by definition, they cannot have complex needs. There is a lack of understanding of the process whereby the carer learns about the needs of the person they are looking after and over time develops an expertise that could be said to *absorb* the complex needs of that person – a process which appears to be invisible to the professionals who become involved when the need for respite care is expressed. The natural outcome of this lack of understanding is a belief that if the cared for person is cared for at home, then anyone can take over that care and that it really isn't that important. Maybe the roots of these attitudes are even more

deep seated within society's denial of illness and disability. The social network circles that I completed with participants (shown in Chapter 5, section 5.12) confirm that the need for respite care is tied up with the loss of friends and family and society's negative attitudes. It is against this backdrop that hospice care offers the comfort and acceptance that service users and carers value so highly.

## **7.5 Reframing respite care as an empathic process**

Through the process of Grounded Theory including the writing of memos, fresh light has been thrown on the qualities of hospice care that service users and carers appreciate so much. Concepts which emerged included needs (being met), protection (dignity and well being), acceptance (being a person) and choice (being allowed) and within these, “expert nursing practice” is shown as described by Harvath et al, (1994, pg 31) being characterized by a blend of scientific knowledge and an understanding of the patient’s unique situation” along with an approach that has been identified as “mindfulness” (Simon et al, 2009) within the hospice multi-disciplinary team. It is not surprising that respite care at the hospice, including in patient and particularly day care, was so important to service users and carers in the study. It often held a central position in the participants’ social network circles and although studies of respite care in hospices are limited and hospice care shown not to be without drawbacks, the literature supports the preference for hospice respite care above other settings (Skilbeck et al, 2005, NAO, 2008). Through the development of concepts, one of the things that the study adds to the literature is a greater theoretical understanding of the component parts of hospice care that make it more acceptable but as the final section of Chapter 6 indicates, my feeling is that there is more to it than this. I believe that service users and carers who access the hospice for respite care feel that their need for respite care is in some way validated and given credibility in a way that doesn’t happen in ‘one size fits all’ settings.

Hospice respite care though, as we know from the study, is not without its tensions and in keeping with the literature (Payne et al, 2004) in discussing respite care with my hospice staff group, there was evidence of ambivalence about providing it and our systems reinforced that it was not seen as being the same and maybe

less important than other types of care eg pain and symptom control and terminal care. Colleagues reported that they had witnessed respite care service users feeling as though they needed to make up symptoms in order to justify their being in a hospice bed which I relate directly to this sense of ambivalence in the staff group. So for all that it is clear that there are many positive aspects to hospices providing respite care which is highly valued by service users and carers, there are still issues around the discursive construct of respite care as discussed in this chapter that lead to a lack of clarity about its purpose and put limitations on its value and positive outcomes.

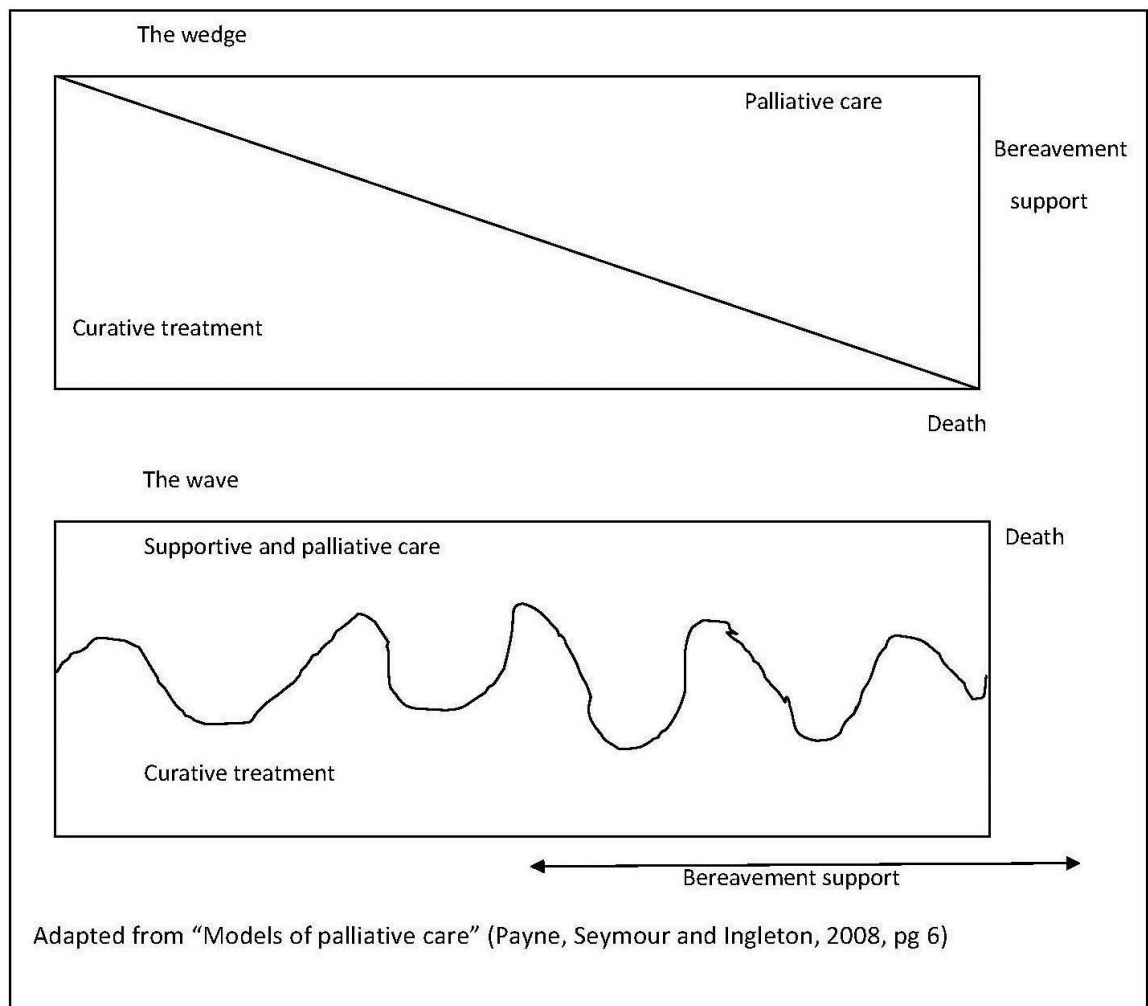
It is clear from the findings of the study that palliative care service users and carers do value acceptable respite care and it is an intervention that despite its drawbacks is seen as essential in sustaining the caring relationship. It is valued by service users and carers when the experience is positive and characterised by an understanding of the complexity of the caring relationship and the needs of both the carer and cared for person. There is a need however for it to be reframed to reflect the fact that it is about supporting a relationship rather than a separation, and acknowledging that within that relationship, there is vulnerability that requires sensitive handling at all times and skilled care. There is also a need to acknowledge that there is an inherent resilience that has the potential to grow if the relationship is protected and supported.

This needs to be done within a framework that incorporates a palliative care approach but is also respectful of chronicity and the more uncertain and long term trajectories of chronic illness (Strauss and Corbin,1988) that were evident in the findings, where the care of the relationship is central and each person is valued in their own right. The following quotation defines the palliative care approach:

“The whole approach is based on the understanding that a person is an indivisible entity, a physical and spiritual being. “The only proper response to a person is respect; a way of seeing and listening to each one in the whole context of their culture and relationships, thereby giving each his or her intrinsic value” (M. Mayne, personal communication)” (Saunders,1996).

The only problem with this is that a palliative care approach as it stands is potentially still limited because in the minds of many, it is still bound up in its traditional associations of what was the relatively short term care of people with cancer and care at the very end of life (Gott et al, 2011). Because of this, it has been acknowledged in the literature that there is a need for a new model of palliative care that includes the care of people who have other conditions that are more chronic than cancer and have more uncertain trajectories (Payne et al, 2008). Payne et al (2008) describe “an emerging model of palliative care” in the form of “a wave” (Fig. 7. 3 below) which put against the more traditional palliative care approach –“the wedge” – shows how the expectations around palliative care have changed over recent years.

Fig. 7.3 Adapted from “Models of palliative care” (Payne, Seymour and Ingleton, 2008, pg 6)



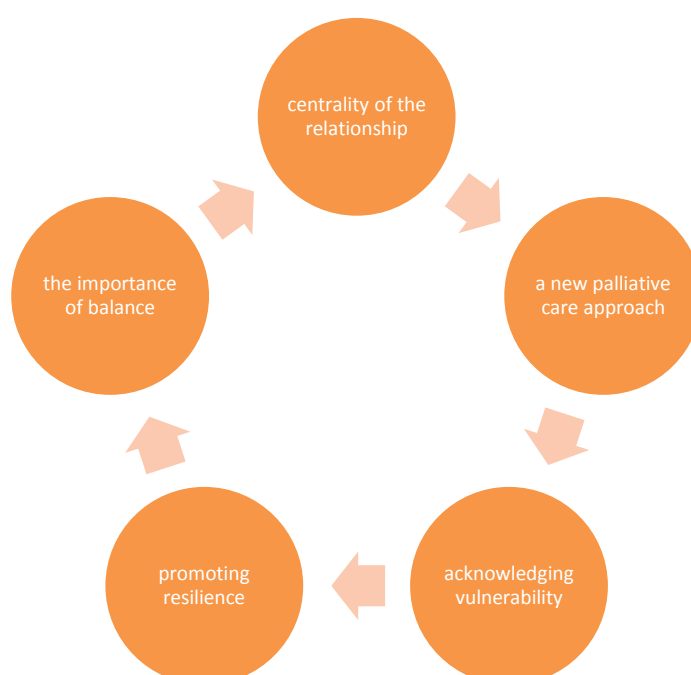
As such, the findings from the study are an expression of that need for a new model of palliative care that recognises the need for support over a potentially long and more uncertain trajectory as defined in “the wave” model. They have shown that the needs for respite care by palliative care service users and carers bring the worlds of chronic illness and palliative care together and the concepts derived from the exploration of service user and carer experience of respite care demonstrate how those worlds are locking together to form a backdrop against which people are receiving respite care.

Strauss and Corbin's model of chronic illness management (1988) adds to our understanding of the needs of palliative care service users and carers and is reflected in the findings of the study. Resilience and vulnerability are acknowledged in their description of a married couple where the husband is debilitated by severe and advanced emphysema. Their "lifelong sense of independence" Strauss and Corbin say "is both their great strength and a cause of their vulnerability. They are vulnerable in the face of severe, prolonged illness which has depleted their resources and energies" (Strauss and Corbin, 1988, pg 120). Within this, there is a call for their care to be managed within a trajectory framework that recognises *home* as being the centre of care and illness as something that is long term, ongoing and characterised by many phases. There is also an acknowledgement of "the key concept of 'arrangements'" (Strauss and Corbin, 1988, pg 53) within the home which need to be supported in order that the balance of life is maintained. Within this framework, "practitioners can combine empathy, knowledge and skill" (Strauss and Corbin, 1988, pg 143) in their care of the service user and their family. The need for empathy and "considering the feelings and concerns of spouses" in the care of service users with chronic illnesses and their partners is also identified in a study by Ellis-Hill (2001, pg 60). As Strauss and Corbin highlight the key concept of "arrangements", Ellis-Hill also recognises the importance of "daily relationships between the individual, their family and friends, health and social care relationships, and wider society in general" (Ellis-Hill, 2001 pg 45). As such, findings from my own study and their implications for practice were enhanced by this sense of the worlds of palliative care and chronic illness management locking together and key messages from both coming together to enhance and develop my understanding of the way respite

care could be reframed to better meet the needs of palliative care service users and carers.

Fig. 7.4 below shows the reframing of respite care which I believe is necessary if it is to fully meet the needs of palliative care service users and carers.

Fig. 7.4 Reframing respite care as an empathic process



Within this cycle, respite care becomes part of an empathic process. I have used a peach colour for the diagram, firstly as with other circle diagrams in the thesis, to ensure that it is not confused with diagrams of a similar style but also, peach is a colour that I believe is associated with empathy and so I felt it was an appropriate colour to use. Within the empathic process as shown in Fig 7.4 above, the centrality of the relationship is a primary concern and the care is delivered within a 'new' palliative care approach. This approach has all the benefits of a traditional palliative care approach as described above but it also acknowledges vulnerability



and promotes resilience within a cyclical context that acknowledges trajectory and the importance of maintaining balance in the relationship over what could be many years rather than weeks and months. The model recognises the importance of empathy in respite care and the fine balance between supporting rather than taking over. This leaves the way open for the concept of respite care to move away from the context of reaction and repair and into the realm of prevention and public health.

Fig.7. 4 is therefore a development of Fig.7.1 at the beginning of this chapter. Fig. 7.4 shows the process within the model for promoting resilience in the caring relationship. As in the first diagram, the empathic process as shown above can only develop if it is underpinned by shared learning which in itself can be described as an empathic process which facilitates learning at both individual and organisational levels (Carr and Clarke, 2010). Thus the model remains open to the development of knowledge and learning.

## **7.6 Reframing respite care as an empathic process: implications for practice**

It was always my intention that any theory generated from my study would have “at least some practical applications” (Strauss and Corbin,1994 pg 281) that may have the potential to inform subsequent service development (Clarke, 1995). As such, I need to devote the final section of this chapter to describe how the reframing of respite care as an empathic process could work in practice for palliative care service users and carers.

The operationalization of reframing respite care as an empathic process rests on the recognition of the importance of a palliative care approach as ‘an ethos’ that is not reliant on being delivered within a hospice setting. However, that is not to say

that hospices shouldn't provide respite care. Wherever it is provided, the approach needs to be sensitive to the more uncertain trajectory of chronic illness as described above. I have defined this as a 'new' palliative care approach. But how can we put this into practice? It may be helpful to think about this in terms of what has emerged to me as the '5 Ps' approach to reframing respite care. While this approach is not a template for implementation, it may be helpful in providing a framework for teams to 'reconsider' respite care and in turn, develop their own new thinking about it. The '5 Ps' are:

- **Process**
- **Paradigm**
- **Practicalities**
- **Practice**
- **Potential**

### **Process**

The study has shown that respite care is not an end in itself and the need for it to be provided within a context that acknowledges trajectory and the importance of maintaining balance in the relationship over months or years is essential. The acknowledgement of respite care as part of a cycle in which the relationship between the cared for person and the carer is central and there is a sense of continuity and ongoing support, starts to reframe respite care as an empathic process.

### **Paradigm**

The study is calling for a paradigm shift that would lift our view of respite care out of its current negative position and into a place that encourages an empathic and

skilled response. This can only come about through shared learning that includes listening to the voices of services users and carers. I would also say that it is reliant on us reconsidering the language of respite care and being more sensitive to the fact that the way we use language has implications for how people are treated and how they feel.

## **Practicalities**

The study has shown that respite care is not straightforward and a one size fits all approach does not work. In theory, the delivery of a new palliative care approach should not have to be limited to hospices. However, there is evidence to say that hospices do offer a unique service that service users and carers particularly value. There is much to debate about whether respite care for palliative care service users and carers is 'specialist' enough to warrant hospice care. In keeping with the literature, I would argue that it often is specialist because of the complexity of the needs involved. However, hospices already care for many patients at the end of life who are asymptomatic but they are there because the hospice is their Preferred Place of Care at the end of their lives. These patients are not specialist but I don't think anyone would argue that they shouldn't access hospice care.

I would say that the findings from the study and the recommendation of 'reframing' respite care should encourage hospices to 'reconsider' respite care. Yes, it is not straightforward and the current palliative care funding review (Hughes-Hallett et al, 2011) although confirming respite care as a "vital service" (Hughes-Hallett et al, 2011, pg 58) has done nothing as yet to add clarity to how it should be provided. However, hospices were founded on innovation and creativity and in a political climate that is looking to create a more diverse and responsive care market, hospices could take opportunities to develop respite care interventions for

palliative care service users and carers that could lead the way in reframing respite care, changing attitudes and improving outcomes.

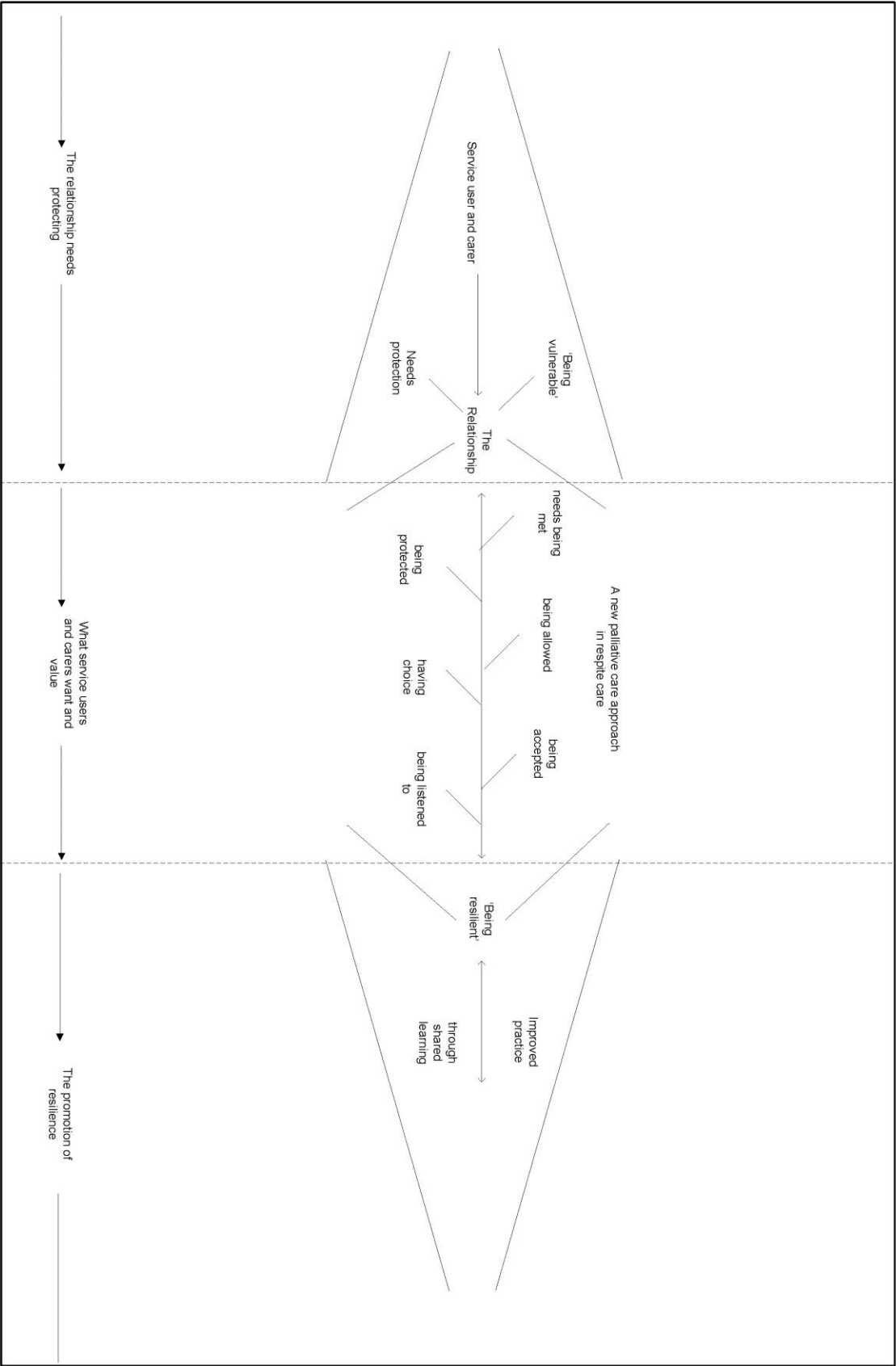
## **Practice**

In reconsidering respite care and reframing it as an empathic process that is underpinned by shared learning and service user and carer involvement, there is the potential for practice to develop that recognises the need for skilled intervention that builds on a model of meeting needs and encouraging resilience. Fig. 7. 5 below shows the theoretical integration of concepts in a new palliative care approach in respite care and as such, it is a guide for practice. As in Fig 5.25 (Chapter 5 Section 5.13) I have divided this diagram into 3 sections for the following reasons:

- To aid clearer textual explanation
- To add clarity to the diagram from a theoretical perspective

As in Fig. 5.25, the running arrow line along the bottom of the diagram once again emphasise the processual nature of the illustration and also the words in each section describe the content of that section and how in turn, one section leads to another:

Fig. 7.5 The theoretical integration of concepts in a new palliative care approach in respite care: a guide for practice



The diagram shows how, by focussing on the the relationship and the need for it to be protected in the first section, needs can be met and resilience can be promoted as shown in the final section of the diagram. The first section of Fig 7.5 shows how 'the relationship needs protecting' and the central section shows the concepts which emerged from the experience of a palliative care approach to respite care. These are shown as 'what service users and carers want and value' and what they felt was important. These concepts such as 'needs being met', 'being allowed', 'being accepted', 'being protected', 'having choice' and 'being listened to' should therefore guide our practice by taking us in to the worlds of service users and carers as they experience them so that we are able to learn and empathise. The central section shows these concepts as being part of 'a new palliative care approach in respite care' which is, as described earlier in this chapter, an approach which incorporates a palliative care approach but is also respectful of chronicity and the more uncertain and long term trajectories of chronic illness. 'The promotion of resilience' as depicted in the final section of the diagram is underpinned by improved practice through shared learning as shown in the final section of Fig 5.25 in Chapter 5. The study does not offer a specific model of practice but it shows what is important to service users and carers and as such, it provides the foundations for caring interventions that are characterised by thoughtfulness, understanding and mindfulness.

A palliative care approach is by defintion, multi-disciplinary, but I am struck by how concepts emerged in the study which reinforced the relationship between a palliative care approach, the fundamental qualities of good nursing and in turn the unique role of the nurse in providing what Henderson describes as "continuous...a complex service" (1966, pg. 17). The respite care literature emphasises the importance of skilled nursing care (Wolkowski et al, 2010) and

through the conceptual density of the study, powerful messages have emerged about the fundamental qualities of nursing that patients and carers value and through which their needs are met. I believe the findings from this study should encourage nurses to recognise the importance of their role in supporting patients and carers within the context of the need for respite care and within this, to reflect on the process of nursing as promoting resilience through being mindful and empathic.

## **Potential**

The reframing of respite care within a new palliative care approach, sits well with dynamic new approaches to supporting family carers (Wolkowski et al, 2010) which call for “a new way forward” (Payne, 2007) that embraces relationship-centred care (Nolan and Ryan, 2011) and the important role of the wider community in enhancing the capabilities of carers (Kellahear, 2009). One might argue that the model I am proposing, by focussing on the vulnerability of the relationship and the need for it to be protected is far too inward looking and cautious to have a place within these aspirations. However, I would argue that what we have learned through this study is that to deny vulnerability and the need for the relationship to be protected leads to the relationship being put at risk. If I can refer back to the spine of vulnerability (Fig. 6.1), unless vulnerability is acknowledged and protection provided, the spine is put under increasing pressure and cracks and fractures inevitably follow. However if vulnerability is acknowledged and the relationship is protected by the sort of empathic process I am proposing, then the spine has the capacity to be strengthened and become resilient. In practice I would say that this means that service users and carers are then more likely to be freed up or empowered to be able to look out from their

relationship and engage with interventions that promote resilience further and enhance their quality of life.

### **7.7 Reframing respite care as an empathic process: implications *in practice***

#### Developing the learning

At the hospice where I work, through a shared learning approach, we are continuing to apply the learning that has emerged from the study. This is a gradual and ongoing process that has included a developing recognition of the complexity intrinsic in the needs for respite care and the attitudes that surround the expression of those needs. Appendix 6 describes some of these interventions and a developing focus on the relationship between the service users and carer rather than the needs of one or the other and also the relationship with the wider community.

Reflections often include analysis of respite care referrals which have been problematic. A recent reflection highlighted issues concerning:

- Community professionals feeling that even though they know themselves that urgent respite care is needed for a patient and carer, they will try and make the referral for pain and symptom control, even if the patient is symptom free, because they feel that there is more chance of the patient being accepted for admission. This of course raises a number of issues including the need to pathologise the patient in order for an admission to the hospice to be acceptable; it gives a mixed message about the importance of respite care and the needs of the carer.
- Staff attitudes to the need for respite care.

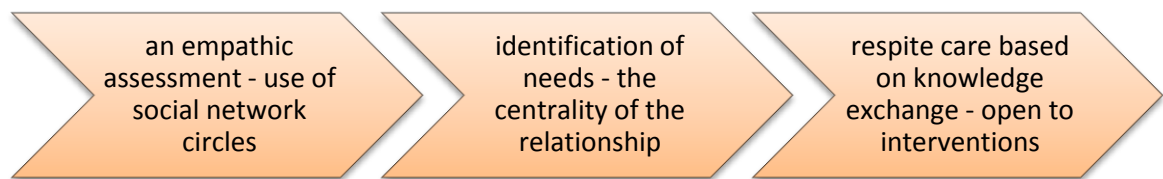


- Psychosocial needs not being perceived by staff as important as other palliative care needs.
- The vulnerability of the caring relationship and the danger of inappropriate hospital admission.
- Lack of support for carers and evidence that they are suffering from dangerous levels of stress.
- Service users feeling guilty about being a burden
- Respite care at the hospice and the offer of family support being appreciated.

As a result of recent reflections, the decision was made for referrals for urgent respite care to be treated in the same way as referrals for pain and symptom control and care at the very end of life. In other words, the complexity of the needs of both service user and carer require a specialist palliative care response and the attention of the multi-disciplinary team.

These reflections reinforce the importance of the findings of the study. They highlight the complex issues around the needs for respite care, the role of the hospice, professional attitudes towards respite care and the importance of an empathic response. Therefore in bringing the reframing of respite care to life, I have identified 3 steps that are integral to the implementation of a new palliative care approach in respite care. These are shown below in Fig. 7.6. The colour used is peach which is a colour that is associated with empathy as described above but the difference in colour also ensures that Fig 7.6 is seen as a development of Fig 7.1 which is at the beginning of this chapter.

Fig. 7.6 Three steps to reframed respite care in practice



The 3 steps in the diagram are described below:

1. **An empathic assessment – use of social network circles:** An empathic response is essential. This implies an attempt to understand the world of the service users and carer as described by them. It is our experience that the facts of a service user and carer’s situation at home ie what services they are receiving, is sometimes different to their experience of it as described by them. This reinforces to me, as I found in the study, that “for staff to recognise the full importance of respite care, they need to see it in the context of the external and internal experiences of the service users and carers as they are living them in their worlds” (Chapter 5, section 5.8). One could say that the truth in the concrete sense of what appears to be happening in that family setting is almost irrelevant in providing a supportive and meaningful response to service users and carers because

it is their experience of it – their truth – that makes their reality and it is within responding to their reality that a difference can be made. In order to enhance this understanding, it may be useful to use the social network circles activity as used as part of my theoretical sampling.

2. **Identification of needs – the centrality of the relationship:** The relationship between the carer and cared for person must be the focus of the identification of needs and the aim should be to provide a response that is sensitive to the importance of maintaining and enhancing balance in the relationship.
3. **Respite care based on knowledge exchange:** The respite care intervention should be based on and encourage knowledge exchange between the carer, the service user and the staff that are temporarily taking over the caring role. Such a response leaves the way open for interventions to take place that may enhance the quality of life of both service user and carer and have the potential to promote resilience.

## **7.8 Recommendations for future research**

In considering recommendations for further research, by definition, this study leaves the way open for further exploration. As already discussed, a constructivist Grounded Theory method has been described as “a discovery process” (Charmaz, 1990) which should encourage us to continue to learn more about the sorts of interventions that the study has indicated are valued by palliative care service users and carers. These may include the following:

- Research which will help us know more about the worlds of palliative care service users and carers as they experience them is important if we are

learn more about them and develop services which are meaningful and helpful to them.

- Further exploration of the value of social network circles as part of an empathic assessment.
- Further exploration of the role of the nurse in supporting palliative care service users and carers within the context of the need for respite care and the promotion of resilience
- Exploration of the role reframed respite care could play in promoting resilience and preventing carer distress and breakdown. Can respite care move away from the context of reaction and repair into the realm of prevention and public health?
- Further investigation into the role hospices could play in the provision of respite care.

## **Chapter 8 Conclusion: reflections on the doctoral journey**

### **8.1 Summary of research journey**

In concluding my thesis and sharing my reflections on my doctoral journey, I feel that a good place to start would be the beginning in the sense of reminding myself and the reader where the journey began and what the primary purpose of the research was “some thousands of words ago” (Trafford and Lesham, 2008 pg 134). The reader may recall that my research question emerged from my practice vision from the hospice in which I work which was to develop a listening culture in which service users and carers would be properly involved in the evaluation and development of services provided by the hospice. It was from hearing the views of service users and carers discussing their generally negative experiences of respite care that I was drawn towards learning more about it. Having established that there were both theoretical and practice concerns regarding respite care in this group of service users and carers, I decided that respite care in palliative care should be my research area and the research topic would be respite care for palliative care service users and carers. More than simply an evaluation of this type of care, by exploring the experiences and perspectives of respite care with service users and carers, I wanted the research to shed some new light on what appeared to be the rather taken for granted notion of respite care which although spoken of in quite a trite way appeared to be hiding many tensions and unanswered questions. The key papers from my initial literature search (Ingleton et al, 2003, Payne et al, 2004, Skilbeck et al, 2005) had all indicated that although the provision of respite care in specialist palliative care was extensive and could be seen as crucial in supporting carers to carry on providing care, that little was known about it and there was a lack of research to support its efficacy. This at a time when UK policy and guidance (NICE, 2004) was recommending that models

of palliative and supportive care should be developed for family carers which may include respite care. The research question which I hoped to answer was therefore as follows:

“Does respite care address the needs of palliative care service users and carers?  
An exploration of their perspectives and experiences of respite care”

and the 3 aims were:

1. To explore the perspectives and experience of palliative care service users and carers of respite care.
2. To establish how far respite care addresses the needs of palliative care service users and carers and whether either party benefit from it.
3. To capture the dynamics of the caring relationship and explore the impact of respite care on the continuity of that relationship.

In order to answer these questions there was no doubt for me that my approach to the research would be qualitative. In keeping with my own learning experience in my journey towards the study, I decided that the methodology which best reflected my own perspective was interpretive. My choice of Grounded Theory as the method emerged from a desire to develop a theory but also for a number of other reasons including the fact that Grounded Theory is considered an appropriate method where there is little known about the area of study and also that there is an expectation that the theory will have some practical application. The type of Grounded Theory I used was informed by the work of Charmaz (2006) who encourages using Grounded Theory strategies flexibly incorporating herself a constructivist approach which was at one with the theoretical underpinnings of my research which were as follows:

- learning from the experiences of service users and carers

- embracing the principles of critical practise
- learning through 'relational endeavour'

As it was my intention to involve service users and carers as much as possible with the research design, I did take opportunities to talk about my research at the hospice's service user forum and carers group in which I handed out preliminary information leaflets. The sampling strategy I used was purposeful in that the inclusion criteria was to be English speaking and have had at least one period of respite care either at the hospice or another setting. Through talking to service users and carers and staff about the research, interest in participating was expressed and once I had received the ethical approval I required, I was able to contact the potential participants to confirm their interest and talk about any concerns they may have before inviting them to agree to consent to participating in the research. At all times, throughout this process and data collection, I adhered to the three principles of ethical concerns in research, these being ensuring consent, protecting confidentiality and balancing the risk of harm with potential benefit (RCN, 2004). I also made it clear that they could withdraw at any point from the study without penalty (Karim, 2000).

The sample was made up of married couples in which a service user with palliative care needs was being cared for by a partner, and bereaved carers of palliative care service users. The service users who had sadly died before I was able to start the data collection had expressed an interest in participating in the research and the agreement that their carers could participate in their own right was agreed through the supervision.

Data collection was carried out by informal in depth individual interviews in the participants' homes. As I was concerned that the comfort of the participants was paramount I offered them the choice of where they would like to be interviewed

and whether, in the case of the married couples, they wished to be interviewed together or separately. All of the participants were interviewed twice apart from one couple who were interviewed three times because of their particular circumstances. In the second round of interviews, a social network circle activity was used as part of theoretical sampling. I also included specific questions in the second interview which were inspired by my returning to the literature review after the first round of interviews. The constant comparative method which is central to a Grounded Theory approach was used throughout data collection and analysis. Within this, data collection occurred in the wider sense in terms of for example discussion with colleagues, supervision, memo writing, keeping field work notes and keeping up to date with the literature. This happened concurrently and beyond the direct work with the participants.

Analysis and interpretation of the data were carried out using Grounded Theory coding strategies and theoretical saturation was reached through the development of increasingly theoretical concepts which shed new light on the concept of respite care. By this stage, the relationship between categories was firmly established and abstract major concepts emerged from the data. A visual representation of the theoretical integration of concepts was presented (Fig 5.25).

## **8.2 Findings from the study: hearing the voice of palliative care service users and carers**

Findings from the study were reported through the concepts that emerged from the data. These were:

- needs and acceptance
- choice and risk
- loss and gains



These concepts emerged from and related to the major concepts which emerged in the study of:

- vulnerability and resilience.

The aim of this chapter was to present the findings in such a way that they would properly show the complexities of the participants' particular worlds. It was also the aim to encourage the reader to be part of the shared experience of making sense of the participants' perspectives on and experience of respite care together as human beings. This was in keeping with a constructivist method but also with the theoretical underpinnings of the research. The findings showed that palliative care service users and carers do value respite care particularly when it is provided within a palliative care approach, and it is important to them. However, the study suggests that there are a number of reasons why it is limited in its value:

- that it is provided on a deficit model of social isolation and limited support
- that it is delivered as an end product in itself
- that it is delivered within a context of mixed messages from society and in turn, providing organisations, which stems from its lack of definition and a lack of clarity about whose needs respite care is supposed to meet.

The tensions within the need for and provision of respite care were discussed further in the Integration and Discussion chapter. Within this chapter, the discussion was developed through the framework of the theoretical concepts that emerged from the study. In order to promote the sense of process and discovery in Grounded Theory the framework was presented as a conceptual map that formed a lens through which the discussion of respite care could be illuminated. The discussion shed light on the many tensions that lay beneath the apparently taken for granted notion of respite care leading us towards the proposed model of reframing respite care as an empathic process.

### **8.3 Reframing respite care as an empathic process: Grounded Theory as practice?**

As I move towards the conclusion of my thesis and reflect on the research journey as reported here, it seems only fitting that I return to the work of Charmaz (2006) who has been a presence throughout my research and whose work has guided me through the Grounded Theory process. In reflecting on the research process herself (Charmaz, 2006), she evaluates Grounded Theory and refers to the criteria for Grounded Theory studies. These include credibility, originality, resonance and usefulness (Charmaz, 2006) and I am hopeful that I have been successful in meeting at least some of the parts that make up the whole of this criteria. However, in terms of a reflection on the usefulness of my study, I was struck by the idea of how well Grounded Theory fits into a model of care that is based on empathy and as such a willingness to enter the multiple worlds of experience which service users and carers occupy:

“Grounded theory methods can provide a route to see beyond the obvious and a path to reach imaginative interpretations” (Charmaz, 2006, pg 181)

In reinforcing the pragmatist philosophy, she explains how pragmatist foundations “encourage an empathetic understanding of research participants’ meanings, actions, and worlds” (Charmaz, 2006, pg 184) which seems entirely in keeping with a nursing approach which I would encourage in the reframing of respite care. Charmaz, (2006) is keen to make this connection between the potential for Grounded Theory to enhance possibilities for us to transform knowledge and my interpretation of that is that what we learn from a Grounded Theory study can directly influence our response to our service users and carers because its foundations are in empathy and it seeks to encourage an imaginative response.

I believe that using Grounded Theory in my study was an appropriate method to use as it is not only in keeping with the theoretical underpinnings of my research but I also believe that its pragmatist foundations have much to offer a nursing model which encourages an empathic and imaginative response to the expressed needs of palliative care service users and carers.

“...when you bring passion, curiosity, openness, and care to your work, novel experiences will ensue and your ideas will emerge”.  
(Charmaz, 2006, pg185)

So before I bring the conclusion to a close and in turn my thesis, I do not feel that I have what may be called a finished product within my work. If I ask, as Charmaz (2006) encourages us to ask, “what purpose does your grounded theory serve?” (Charmaz, 2006, pg 184) my feeling is that my Grounded Theory will be relevant in practice as it enhances the possibility for nurses as part of a multi-disciplinary team, to be part of the worlds of their patients and perform that unique, continuous role which Henderson (1966) identified so many years ago as fundamental to nursing.

#### **8.4 Strengths and limitations of the study**

The content of the previous section is an indication of the strength of the study. That a constructivist grounded theory method fits well with the question, the design and philosophy of the research must be considered positive. The other strength implicit in this is that the pragmatist foundations of the method can directly influence practice. Pragmatism assumes people are active and creative, and therefore there is a sense of potential for staff as well as both service users and carers. From a personal perspective, the method captures my experience of the doctoral journey as a learning process which does not come to an end simply because the study is completed and the thesis is written.

From a methodological perspective, I believe Grounded Theory was an appropriate method for me to use to explore the perspectives of palliative care service users and carers as my aim was to develop a theory. It was also important that the method allowed participants to tell their own stories in their own way. The method is respectful of the multiple truths within the experiences of the participants and it allows the large amounts of data to be rendered conceptually towards more theoretical statements (Charmaz, 1990).

A limitation of the study could be seen to be that the sample was small. However, I do not see this as a limitation. Because the method allows the researcher to explore perspectives and experiences in such depth, the result is a conceptual density that can provide significant insights into the experiences and perspectives of service users and carers in a way that would not be possible with whatever one might consider a 'large' sample to be. That is not to say that I would not have liked to have included more service users and carers in the study but within the limitations of the course, along with the well documented difficulties of recruiting palliative care service users and carers to research studies, I am satisfied that the sample I did recruit allowed the study to produce a deepened understanding of the experiences and perspectives of respite care for palliative care service users and carers that does have the capacity to influence practice.

Another strength of the study was that the sample was made up of services users who had diagnoses that have not received the same research attention as some other palliative care groups. This reinforces that the study was able to capture the voices of palliative care service users and carers who in the context of other palliative care research, may be considered to be at a disadvantage.

Lastly, I believe a limitation of the study is that as I reflect on it, I can think of things that I could have done better and as I discussed in the chapter on ethical considerations, I do feel a great responsibility towards the participants in the study in ensuring that their voice is heard. My research journey has not been without some significant personal events of my own and although these events necessarily diverted my attention away from my studies at times, I feel that the experiences have enhanced my theoretical sensitivity and have reinforced my understanding of reflexivity and my role within the research process.

### **8.5 Reflections on a constructivist Grounded Theory study: a fresh perspective on respite care?**

There can be no doubt that as people live longer with palliative care needs, the needs of both service users and carers will change as both parties have to adapt to the chronic and more complex nature of the experience of caring and being cared for. Added to this, the experience is likely to take place against a backdrop of decreasing resources and increasingly fragmented family relationships. Within this context, it would have been unrealistic for me to think that whatever theory my study generated could hold all of the answers to the many challenges that the changing landscape of palliative and end of life care raises. In any case, it would also have been out of step with the theoretical underpinnings of the research as well as its aims. However, what the study has done is illuminate our understanding of the experiences and perspectives of respite care as experienced by palliative care service users and carers in the context of their relationship. Through the development of concepts, while we may not have all the answers, fresh light has been thrown on the little investigated subject of respite care and as a result there is an increased clarity about its purpose and what it means to service users and

carers. Added to this, we are able to see more clearly how respite care is experienced and how its outcomes could be improved. These discoveries are made all the more significant in the light of policy aims to enable patient choice towards the end of life, an increase in deaths at home and the decrease of inappropriate hospital admissions (DOH, 2008, NAO, 2008). While the literature has acknowledged that the successful achievement of these aims is reliant on carers being supported (Grande et al, 2009), the study offers fresh insights into the importance of the role of respite care within that discourse.

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#### Review

# What does respite care mean for palliative care service users and carers? Messages from a conceptual mapping

Anna Wolkowski, Susan M Carr, Charlotte L Clarke

## Abstract

Over the coming years, as an ageing population with multiple chronic illnesses increases, the number of carers and paid carers is set to decrease. There is, therefore, an urgent need to understand what types of services are most supportive in helping to sustain caring relationships. Respite care is frequently mentioned as a key factor in supporting family carers and improving their quality of life but there is a lack of research to support its efficacy. This paper will present a conceptual map of respite care in order to promote a greater understanding of the multiple tensions that the palliative care respite literature reveals. As learning more about carer's needs and the complexities of the caring relationship develops, it is an appropriate time to map the key messages from the literature to help us understand what respite care does actually mean to palliative care service users and carers.

**Key words:** Carers ● Concept maps ● Palliative care ● Person-centred care ● Public health approach ● Relationship-centred care ● Respite care

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There are indications that over the coming years an increasing amount of support for carers of patients with palliative care needs will be required. The literature refers to pressure in the UK, Europe and Australia, and the reasons for this include the fact that there is an ageing population, with fewer carers and paid carers, and increasing numbers of people with chronic illnesses requiring care (McNally et al, 1999; Palliative Care Australia (PCA), 2005; European Association for Palliative Care (EAPC), 2009; Grande et al, 2009). There are also changing patterns of care (Zapart et al, 2007), and in the UK and Australia, for example, studies have shown that up to 90% of patients with terminal cancer now spend the majority of their last year of life at home (Samar et al, 2005; Skilbeck et al, 2005). Such changes are also reflected in varying ways across Europe, the US and other parts of the world (Newton et al 2002; van Exel et al, 2006; Honca et al, 2007; EAPC, 2009) making this an international issue.

In recent UK policy and guidance (National

Institute of Clinical Excellence (NICE) 2004; Department of Health (DH), 2005; 2006; 2008a; 2008b) respite care is frequently mentioned as a key factor in supporting carers so that they may carry on caring for longer and have an improved quality of life. However, from an accumulative review of the literature over the last 3 years, it is difficult to see how respite care could have established itself as being of such value. Studies have shown that there is a lack of research to support its efficacy (McNally et al, 1999; Ingelton et al, 2003) and little is known about respite services for patients with a life-limiting illness (Owen and Johnson, 2005; Skilbeck et al, 2005). Anecdotal evidence which favours respite care though is very strong and it is almost as if it is so strong that it does not require research.

In this paper the authors will present a conceptual map of the key messages from the literature. Concept maps are used to organize and represent knowledge and in so doing, help the reader construct new meanings in the subject (Novak, 1991). It is hoped that the reader's understanding of the apparently straightforward concept of respite care will be enhanced (Figure 1).

The article will also discuss new approaches to our understanding of what respite care is, and what it means to palliative care service users and carers. It is worth noting at this point that it is becoming increasingly difficult to define exactly who the palliative care population is, as palliative care services move away from the provision of care that concentrated mainly on people with cancer to include people with other conditions (Payne et al, 2008). For the purposes of this article, literature relating to people with dementia has not been included but it is important to acknowledge that there is already a substantial body of knowledge about the problems associated with caring for a person with dementia (Clarke, 1999).

## The definition and purpose of respite care

The term 'respite care' can refer to inpatient, day or home-based provision. Respite care has recently



been described as being considered to be 'the cornerstone of care' for many patient populations (McGrath et al, 2006). Respite care in palliative care is mentioned frequently in recent UK policy and guidance and is seen as a 'key need' for family carers of patients with palliative care needs (Barrett et al, 2009). However, there is currently no consensus definition of respite with clear criteria agreed for the purpose of respite services (Payne et al, 2004), with hospices themselves having no clear definition of respite care either (Satterley, 2007). A definition used by Payne et al (2004) in their survey of the perspectives of specialist palliative care providers of inpatient respite in the UK, is based on the assumption that respite is predominantly for the benefit of carers. But while the majority of respondents agreed with this definition, a large proportion disagreed, as they thought that respite should predominantly benefit the patient or mutually benefit the patient and carer. So although it is generally accepted that in respite care it is the carer who is intended to be the direct beneficiary (Ingleton et al, 2003) this is not made clear in the literature.

If the primary purpose of respite care is to benefit the carer, one might assume that patients would not necessarily require medical or nursing interventions during respite (Satterley, 2007) above what they would normally receive at home. However, a number of UK studies have shown that this is not the case, with the most commonly reported reason for respite care in hospices being the patient's symptom management (Hicks and Corcoran, 1993; Owen and Johnson, 2005; Satterley, 2007). Added to this, the definitional blurring is further compounded by the idea that referral for respite care to specialist palliative care services (SPCS) often functions more to support members of the health-care team who may be struggling to manage a complex care situation, rather than assisting the informal carer with the provision of respite care (Ingleton et al, 2003). It appears, therefore, that there is 'a basic problem of definition' (Johnson, 2005) of respite care in palliative care both nationally and internationally. The EAPC (2009) have pointed out that a lack of common terminology in palliative care across Europe and the rest of the world has hampered the development of international standards. As such, the development of a consensus definition of respite and the agreement of a clear criteria for the purpose of respite services would be helpful (Payne et al, 2004).

### Existing evidence base

A lack of research is referred to throughout the literature and studies, audits and systematic reviews specifically about respite care for patients with

cancer or palliative care needs are limited, (Hicks and Corcoran, 1993; Strang et al, 2002; Kristjanson et al, 2004; Payne et al, 2004; Owen and Johnson, 2005; Skilbeck et al, 2005; McGrath et al, 2006; van Excel, 2006; Satterley, 2007; Barrett et al, 2009). In a UK systematic review, which is often referred to in the palliative care literature as highlighting the evidence of the lack of research in this area, McNally et al (1999) identify 29 studies about respite care with different types of patients. Skilbeck et al (2005) stated that studies have tended to concentrate on patients with dementia, stroke, and those who are frail and elderly (McNally et al, 1999). This is not to say that they may not be relevant to issues around respite care for patients with palliative care needs—indeed, we would now probably say that these groups of patients would be redefined as having palliative care needs. The problem of definition in respite care also extends to the problem of definition in palliative care as the distinction between 'acute' and 'chronic' diseases continue to blur owing to changes in the diseases themselves, medical technology and treatment (Payne and Seymour, 2008). It is likely that these problems of definition make studying the effects of respite care problematic (Ingleton et al, 2003) which may well go at least some way to explaining why there is a lack of research on respite care in relation to palliative and end-of-life care. This may also indicate that the 'umbrella' term of respite care is no longer appropriate. The reality is that little is known about respite services for patients with life-limiting illnesses (Skilbeck et al, 2005) and so emerges one of the many tensions in this issue. Here is something, apparently so valued and so much needed. It is 'mentioned repeatedly' by carers in the consultations around the Strategy (DH, 2008a) and seen as the most commonly reported need for carers of

Figure 1. Conceptual map



*‘The literature is starting to acknowledge that providing respite care is not as straightforward as it might initially seem’<sup>9</sup>*

palliative care patients (Harding and Higginson, 2001) but with virtually no evidence in the literature to support its apparent value. Even now, as the body of evidence grows about carers' needs, there is still a lack of evidence about how best to address them (Grande et al, 2009).

### The role of hospices and specialist palliative care services

Despite a lack of evidence promoting its worth and a lack of clarity about what it actually is, in the UK, respite care provision in specialist palliative care settings, namely hospices, is considerable (Payne et al, 2004) and apparently underpinned only by largely implicit assumptions of its value (Ingleton et al, 2003). Little is known about respite services in hospices (Payne et al, 2004) although respite care is said to be an important component of provision (Ingleton et al, 2003) through which patients have much to gain (Hicks and Corcoran, 1993). At the same time, there is evidence of an ambivalence toward providing respite care that seems to have its roots in the lack of consensus on the purpose of inpatient respite care. This ambivalence may well have led to a sizeable proportion of hospices and SPCSs no longer providing this service. The lack of an agreed definition and purpose of respite care runs through the hospice and SPCS literature. Hicks and Corcoran (1993), Owen and Johnson (2005) and Satterley (2007) all agree that respite care in hospices is rarely straightforward and 'significant interventions' (Owen and Johnson, 2005) are often required by patients. So on the one hand, the literature suggests that a number of hospices no longer provide respite services as they do not see it as their role. On the other hand, it would seem that respite care for palliative care patients is usually complex and specialist by nature (Owen and Johnson, 2005) suggesting that more general care, i.e. in a nursing home, would simply not be adequate. In terms of what this means to service users and carers, the literature suggests that a move toward less hospice care would not be welcomed. In the recent National Audit Office Report on patient and carer experiences of end-of-life care in England (2008), patients and carers specifically identified hospices as the preferred place for respite care. However, we know that even with hospice respite care, carers worry about whether the person they care for will be looked after properly (Skilbeck et al, 2005) making them ambivalent about using the service.

### Needs and acceptance

As well as there being an apparently ambivalent attitude towards the provision of respite care, the

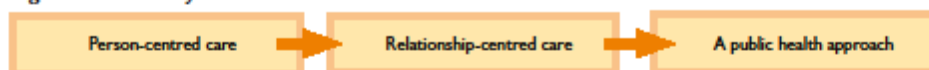
literature shows that despite the apparent need for it, carers of patients with palliative care needs are also ambivalent about receiving respite care. In two papers, Harding and Higginson (2001; 2003) describe how carers are highly ambivalent about their own needs. Time away from caring was the most commonly reported need in a study of 18 caregivers, but it was also the most difficult to meet owing to the carers' ambivalence about making the time (Harding and Higginson, 2001). In this context, respite care, although providing much needed time away from the caring role, may prove unacceptable to those carers unwilling to leave the person they are caring for (Harding and Higginson, 2003). They also say that respite care literature has 'rarely answered questions of acceptability' among this population. The discussion is set in the context of a systematic literature review about carer interventions in cancer and palliative care.

By acknowledging this ambivalence toward respite care the literature is starting to acknowledge that providing it is not as straightforward as it might initially seem (EAPC, 2009). This is evident in the fact that even when a service that is one of the most requested forms of support is available, uptake of respite care is low (Ingleton et al, 2003). The literature suggests some reasons why this might be the case, i.e. that the care offered is not of a suitable quality (Ingleton et al, 2003). However, it is also a clue to the uncovering of more complex issues concerned with the caring relationship and accepting support. The more recent literature talks about this complexity (EAPC, 2009; Kellahear, 2009) not only in terms of respite care but in the context of supportive interventions for carers and how it is likely to become more complex as people are likely to die in older age suffering from a number of co-morbidities along with sensory and cognitive impairments (EAPC, 2009). So, if interventions like respite care, in whatever form it comes, stand any chance of working in the way they are expected to work, there needs to be a better understanding of the complex issues surrounding the expression of need and the acceptance of help (Grande et al, 2009).

### Models of care

There is increasing evidence that understanding the complex issues around needs and acceptance of support in family carers would be helped by services adopting an approach that acknowledged that caregiving can only be understood in the context of a relationship, which includes patient, carers and staff (Nolan et al, 2001). This approach is known as relationship-centred care (Nolan et al, 2001) and it marks a move away from the notion

Figure 2. Models of care



of person-centred care. It is promoted in the literature as a positive way forward in determining the needs of family carers and the person they are caring for (Payne, 2007; Kellaher, 2009; Payne and Hudson, 2009). Within the context of this literature, the lack of evidence supporting the efficacy of respite care is reinforced. The concept of respite care is framed within the deficit model of carer burden (Ingleton et al, 2003) in which the cared for person has to be taken away to give the carer a 'rest' (Payne, 2007). The view is that this approach, while helpful in some ways, does nothing to reinforce the expertise of the carer and ultimately the resilience of the family to cope with the demands of caring.

A natural progression from, and including, relationship-centred care is that we exist in our relationship with others and our surroundings (Clarke, 1999). A public health approach acknowledges the contribution of not only the cared for person, the carer and the staff but also the wider community (Figure 2). Kellaher (2009) describes models of palliative care from Australia to reinforce the important role the wider community can play in enhancing the capabilities of carers. This approach builds on the deficit model of respite care which is helpful to carers only because it is set against a world where carers are subject to poor social support, discrimination and social isolation. In this world, respite care is a 'sticking plaster' or a 'repair' strategy (Grande et al, 2009), as opposed to a preventative strengthening strategy. In this world, strategies for strengthening families and communities are seen as ultimately more positive and more helpful than traditional respite care alone (Kellaher, 2009).

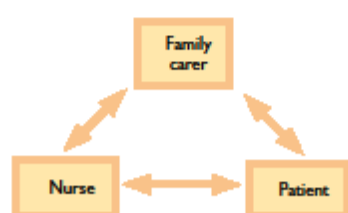


Figure 3. Adapted from the participant triad in the community nursing context (Carr, 2004)

### The role of the nurse


Australian studies have shown that respite care provided in the home by nurses is highly valued (Kristjansson et al, 2004; Barrett et al, 2009). This emphasizes the importance to carers of a qualified nurse in providing skilled care for the patient. In a US study, Honca et al (2007) found that nurses are in a unique position to assess caregiver strain and burden and to provide appropriate interventions. In a UK study, Bliss (2006) suggests that district nurses have an important role in assisting with the carers' assessment process. We should be careful, however, of over simplifying the concept of care by solely focusing on one party's needs. This partial approach, which has been noted as being common in care policy (Forbat, 2008), runs the risk of contributing to the polarization of carer and cared for person, thus potentially denying the needs of the cared for person as well as the very complexity that the current literature is rightly starting to acknowledge. Nurses in the community have been used for some time to working in a collaborative way with patients and carers, even though there is limited guidance or literature on how to achieve this and deal with the clinical reasoning consequences (Carr, 2004). Carr describes the ethical dilemmas that community nurses have to grapple with when there is a conflict between the needs of the patient and those of the carer. A relevant example is given of a carer being keen to take up the offer of respite care when the patient was not. The nurse is trying to take both views into account but acknowledges that 'it's difficult to know whose view to support' (Carr, 2004). This example demonstrates the complex issues that lie beneath what appears to be a simple offer of support, and it emphasizes the role of the nurse as a clinician who is in an ideal position to acknowledge the needs of the carer and the cared for person, and somehow act as a broker between the two.

### Conclusion

There is nothing straightforward about respite care for palliative care service users and carers. There is a problem with defining respite care. An umbrella term is no longer acceptable and there are too many variables now to take a one-size-fits-all approach. The definition of a palliative care patient is increasingly blurred. Diseases are less acute,



more chronic, and different diseases bring different trajectories and different problems. Added to this are the complexities of family relationships and the issues around needs and acceptance make the term 'respite care' on its own seem increasingly trite, inadequate and outdated in terms of addressing the needs of people with such complex needs.

Dynamic new approaches to supporting family carers suggest that strategies with a public health focus aimed at strengthening relationships and communities and promoting resilience will be more helpful to carers in the long run, making the most of their expertise rather than just temporarily relieving them of their duties. However, at the moment respite care remains the most commonly described carer need. In developing new approaches, we cannot ignore what service users and carers are saying is most important for them but we do need to know more about it. And maybe there is a need to look at how respite care services can be developed that are not just about repair but about promoting resilience too. Also, the skills needed to deliver relationship-centred care, which by definition, requires clinicians to take the needs of both the carer and cared for into account, should not be underestimated. This is not acknowledged in the literature but may well be a challenge which, within the context of a multidisciplinary team, the nurse is ideally placed to firmly grasp and take forward. 

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## **Appendix 2**

**Preliminary information on research proposal involving service users and carers at , Thursday 17<sup>th</sup> January, 2008.**  
**Research to be carried out by Anna Wolkowski, Director of Clinical Services,**  
**/Doctorate of Nursing Science Research student,**  
**Northumbria University.**

### **Background:**

Current evidence indicates that an increasing amount of support for carers of patients with palliative care needs will be required as time goes on. Although respite care is spoken of frequently in guidance, little is known about respite services for patients with life limiting illnesses and services appear to have developed on the assumption that they are “a good thing”. Further studies are required to fill this gap in knowledge and to help to shape service provision.

### **Title of study:**

Does respite care address the needs of palliative care service users and carers? A study involving service users and carers in an exploration of their perspectives and experience of respite care.

### **The purpose of the study:**

To establish whether respite care addresses the needs of palliative care service users and carers.

### **The aims and objectives of the study:**

- 1 To explore the perspectives and experiences of palliative care service users and carers of respite care.
- 2 To establish how far respite care addresses the needs of palliative care service users and carers and whether either party benefit from it.
- 3 To capture the dynamics of the caring relationship and explore the impact of respite care on the continuity of that relationship.

An application for ethical approval of the study will be made shortly.

**“Does respite care address the needs of palliative care service users and carers? A study involving service users and carers in an exploration of their perspectives and experience of respite care.”**

### **Information sheet for participants**

**Researcher: Anna Wolkowski, Director of Clinical Services,  
and Doctorate of Nursing Science research  
student, Northumbria University.**

**This sheet will tell you about the research I am carrying out and how you can be involved.**

#### **Part A Information about the research study**

##### **The purpose of the study:**

To establish how respite care addresses the needs of palliative care service users and carers.

##### **The aims and objectives of the study:**

- 1 To explore the perspectives and experiences of palliative care service users and carers of respite care.
- 2 To establish how far respite care addresses the needs of palliative care service users and carers and if either party benefit from it.
- 3 To capture the dynamics of the caring relationship and explore the impact of respite care on the continuity of that relationship.

##### **What is the research about?**

The aim of the research is to find out more about respite care as it is experienced by service users and carers at .

## **Why do research about respite care?**

Current evidence indicates that an increasing amount of support for carers of patients with palliative care needs will be required as time goes on. Although respite care is talked about a lot and mentioned frequently in reports that the government produce about how services should be provided for people, little is known about respite services for patients with life limiting illnesses and if respite care meets their needs or their carers' needs.

People who have done some research on respite care all agree that further studies are required to fill the gap in knowledge and to help shape the way services are provided.

## **What will the major outcomes of the research be?**

I hope that the outcomes of the research will help to shape the way services are provided locally. I will therefore be keen to share the outcomes of the research with service users, carers, staff and board members at . I would also hope to tell other service users, carers and professionals from other areas by speaking at meetings, through publications and conferences.

## **Why involve service users and carers?**

Research that has been done so far has concentrated on the perspectives of organisations and staff. This research will explore the views of service users and carers so that we can gain an understanding of your experiences and your needs from your point of view.

## **Questions you may want to ask me:**

## **How will I know if I am suitable to take part in the research?**

You would need to be an English speaking service user who has experienced at least one period of respite care at the hospice or another care setting. You will be asked to nominate your carer who would also be interviewed. They would need to be over 18 years of age.

### **If I take part in the research, what will I have to do?**

You would need to be prepared for me to talk to you and your carer, separately or together, in individual informal interviews. I would ask you questions about your experiences of respite care but there would be no set questions or structure to adhere to. Your comfort during these interviews would be the most important thing, so I could meet with you at the hospice or in your own home. I would most likely need to meet with you and your carer more than once so that I could have as full an understanding as possible of your experiences. The time and length of the interviews would be arranged with you and your carer at your convenience. The interviews will take place over several months in 2008-2009. You can opt out of the research at any time if you wish to.

### **What will happen to the information you collect from me during the interviews?**

Everything you and your carer say will be listened to and the interviews will be recorded on a digital audio recorder. This is so that I will not be distracted by taking notes and can concentrate on what you are saying. I will then be able to transcribe and analyse the information you have given me in order to answer my research question. The records of the interviews will be stored safely and securely at during the time I am researching my question. On completion of the research, they will be kept for 8 years in the same way as any other patient records are kept at the hospice. After this period, they will be destroyed.

### **Will anyone else know about the information I give you?**

All the information I collect from you and your carer during the interviews will only be viewed by me and my supervisor at Northumbria University. Individuals will not be identified in any publication or dissemination of the research findings without your explicit consent.

### **What happens if I do not want to participate in the study?**

You are entirely free to decide whether you want to be involved or not. The decision you make will not, in any way, affect the care you receive at the hospice.

### **What happens if I agree to participate in the study and then change my mind?**



You will be completely free to change your mind about participating at any time. The decision you make will not in any way affect the care you receive at the hospice.

### **Who is the researcher?**

I am Director of Clinical Services at \_\_\_\_\_, and I am very interested in how we provide respite care. However, I am doing this research as part of my doctoral research at Northumbria University. As such, it is important that participants understand that generally speaking I will not be able to respond directly or 'intervene' in concerns a service user or carer may express about services provided by \_\_\_\_\_ during the interviews. Any concerns about the care provided by the hospice should be addressed through the normal channels.

### **What course is the researcher studying?**

I am studying for a doctorate of nursing science. This qualification is called a professional doctorate in that it is about practice rather than theory and in order to achieve it, I have to show that I am developing practice. By doing this research, I am using the skills that I have developed over many years of being a practitioner in order to learn from service users and carers to develop practice that reflects this learning.

### **What if I would like to know more about the research or ask more questions?**

If you do not understand something or you want to ask more questions, you can telephone me on \_\_\_\_\_, or email me on \_\_\_\_\_.

### **What if I am unhappy about you or any aspect of the research?**

If you are not happy about any aspect of the research, you can telephone \_\_\_\_\_ (Chief Executive) at \_\_\_\_\_ or email \_\_\_\_\_.

### **Part B Declaration to participants**

- Individuals will not be identified in any publication or discussion of the research findings without their explicit content.

- All information collected during the interviews will only be viewed by the researcher and her supervisor if requested, and remain strictly confidential.
- If you and your carer take part in the study you have the right among other things to:

Refuse to answer any particular question and to withdraw from the study at any time.

Ask any further questions about the study that occur to you during your participation.

Be given access to a summary of the findings from the study when it is concluded.

**Researcher's name:** . . . . .

**Researcher's signature:** . . . . .

**Contact details:**

**Date:** . . . . .

## Appendix 4

**Does respite care address the needs of palliative care service users and carers? A study involving service users and carers in an exploration of their perspectives and experience of respite care.**

### Invitation Letter

**Researcher: Anna Wolkowski, Doctorate of Nursing Science research student, Northumbria University and Director of Clinical Services,** .

28<sup>th</sup> March 2008

Name

Address

Dear

I would like to invite you and the person who cares for you to take part in the following study:

**“Does respite care address the needs of palliative care service users and carers?**

**A study involving service users and carers in our exploration of their perspectives and experience of respite care”**

My name is Anna Wolkowski. I am director of clinical services at the hospice, but I am doing this research as a research student studying for the award of Doctorate of Nursing Science at Northumbria University. In my role at the hospice, I do have a great interest in respite care, but it is important to say that I am carrying out this

research on respite care as a student who is keen to learn about your experiences.

The purpose of the study is to establish how respite care addresses the needs of palliative care service users and carers from their points of view.

It is anticipated that findings from the study may help to shape the way respite services are provided at . They may also be of interest to other organizations which provide respite care services.

Little is known about respite services for patients with life limiting illnesses. By taking part in this study, you will be helping us to find out more about respite care and if it addresses your needs. This will help to fill the current gap in knowledge in this area.

If you feel you might be interested in taking part in the study, please read the enclosed information sheet. This will tell you more about the study and hopefully answer any questions you may have. If you would like to be involved in the study, or if you would like to ask more questions, please telephone me on , or email me on .

Thank you for your interest.

Yours sincerely

**Anna Wolkowski**  
**Doctorate of Nursing Science Research Student, Northumbria**  
**University**  
**and**  
**Director of Clinical Services,**

**Does respite care address the needs of palliative care service users and carers? A study involving service users and carers in an exploration of their perspectives and experience of respite care.**

## Consent Form

**Researcher: Anna Wolkowski, Director of Clinical Services, and Doctorate of Nursing Science research student, Northumbria University.**

**Contact details :** \_\_\_\_\_ or email \_\_\_\_\_

Please tick box

- 1 I have read and understood the information sheet ☐
- 2 I have been able to ask questions and these have been answered to my satisfaction ☐
- 3 I am willing to be interviewed ☐
- 4 I am happy for the interviews to be tape recorded ☐
- 5 I understand that I can withdraw from the study at any time if I want to ☐
- 6 I do not have to tell anyone why I want to withdraw and my decision will not affect the care I receive from the hospice ☐
- 7 I know that my name and details will be kept confidential and will not appear in any printed documents ☐
- 8 I am happy to have what I have said in the interviews included in the printed documents ☐
- 9 I am happy to take part in the above study ☐

**My name** ..... **Date** / / **Signature or mark** .....

Researcher ..... Date   /   /   Signature or mark .....

Witness ..... Date / / Signature or mark .....  
(where person unable to sign)

## Appendix 6: Ethical Approval, Letters/E-mails



School of Health, Community and Education Studies  
Postgraduate and Research Support Office  
Room H007  
Coast Lane Campus East  
Newcastle upon Tyne NE7 7XA

Tel: 0191 215 6276

anna.kennedy@nunn.ac.uk

13 June 2008

Anna Wolkowski

15 JUN 2008

Dear Anna

**School of HCES Research Ethics Sub Committee**

**Title: Does respite care address the needs of palliative care service users and carers?**

**A study involving service users and carers in an exploration of their perspectives and experience of respite care.**

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and that the University Policies on Ethics and Consent are followed.

You may now also proceed with your application (if applicable) to:

- NHS organisations for Trust approval where appropriate.
- National Research Ethics Service (NRES). [Please forward a copy of this letter where appropriate plus the peer review comments and your response to those comments]  
**Please notify the University once you obtain NRES / REC favourable opinion.**

**NB:** If an alternative information sheet is developed it will need to be submitted to this office.

**IMPORTANT: PLEASE FORWARD A COPY OF YOUR NRES / REC APPROVAL LETTER TO THE ABOVE ADDRESS.**

- Where appropriate you will also need honorary contract(s) with Trusts. **Please forward a copy of any agreed honorary contracts to the above address.**
- Note that occupational health and criminal records bureau clearance will also be required if working with children or vulnerable adults.
- Where necessary, the Committee will be willing to forward the independent peer review forms to relevant external research ethics committees upon receipt of a signed request from yourself.

**All researchers must also notify this office of the following:**

- Commencement and completion of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;

School of Health, Community and Education Studies  
Dean: Professor Rayston Stephens


Postgraduate and Research Support Office

- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

A handwritten signature in black ink, appearing to be 'TK' or similar, written in a cursive style.

 Dr Tina Cook

**Anna Wolkowski**

---

**From:** Sue Carr [sue.carr@unn.ac.uk]  
**Sent:** 01 October 2007 11:39  
**To:** Anna Wolkowski  
**Subject:** FW: NRES applications

fyi

S

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**From:** Tina Cook  
**Sent:** 01 October 2007 10:24  
**To:** Joanna Reynolds  
**Cc:** Sue Carr  
**Subject:** RE: NRES applications

*National Research Ethics Service*

This is the basic information from the NRES (formerly COREC) site ( See below) – this is always the best place to have a look as it has all the latest information, although sometimes it can be tricky to find as it is not well laid out to my thinking. There is more on this subject so if you are unclear you might need to take a look yourself.

Basically, what it says is that if any research participants are recruited through the NHS then formal submission through an LREC is necessary. If a researcher recruited everyone through the hospice that was not NHS, in the same way as if you recruited through a school, NHS scrutiny would not be necessary.

Hope this helps your student in designing her/his research Sue.

Regards

Tina.

3.1 Ethical advice from the appropriate NHS REC is required for any research proposal involving:

- a. patients and users of the NHS. This includes all potential research participants recruited by virtue of the patient or user's past or present treatment by, or use of, the NHS. It includes NHS patients treated under contracts with private sector institutions
- b. individuals identified as potential research participants because of their status as relatives or carers of patients and users of the NHS, as defined above
- c. access to data, organs or other bodily material of past and present NHS patients
- d. fetal material and IVF involving NHS patients
- e. the recently dead in NHS premises
- f. the use of, or potential access to, NHS premises or facilities
- g. NHS staff - recruited as research participants by virtue of their professional role."



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**From:** Joanna Reynolds  
**Sent:** 28 September 2007 10:14  
**To:** Tina Cook  
**Cc:** Sue Carr  
**Subject:** NRES applications

Hi Tina

I wonder if you could clarify a query re: whether NRES (formally LREC) approval would be necessary? Sue Carr has a doctoral student who is working in a hospice and will be conducting her research in the hospice. She will not be conducting research on NHS property, she is not an NHS employee and she will not be interviewing any NHS practitioners. Some of the hospice patients who will be included in the study may be referred from NHS practitioners (some will be self referrals) - would NRES approval be necessary if some proportion of referrals into a study are referred by NHS practitioners? I wondered if there is a proportion that falls below NRES radar? eg one or two?

I suggested its best to check with the local R&D dept, as it might be that they would just need to get R&D approval. Since i am assisting you in your management role with the ethics, I suggested to Sue that I would ask for your advice on this matter for her,

many thanks

joanna

Dr. Joanna Reynolds

Research Psychologist

Northumbria University

School of Health, Community and Education Studies

Research Centre

Room H011

Coach Lane Campus, East

Benton

Newcastle-upon-Tyne

NE7 7XA

[joanna2.reynolds@unn.ac.uk](mailto:joanna2.reynolds@unn.ac.uk)


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


3

**Anna Wolkowski**

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**From:**   
**Sent:** 03 September 2008 13:10  
**To:** Anna Wolkowski  
**Subject:** FW:  
**Attachments:** Approval letter.doc; Invitation letter 3; Information sheet for participants 3; Consent Form.2A.docx; Research Proposal Text 3A.docx





---

**From:** Anna Wolkowski  
**Sent:** 07 August 2008 12:35  
**To:**   
**Cc:**   
**Subject:** 


Dear 

**Re hospice ethical approval for my research :**


**'Does respite care address the needs of palliative care service users and carers? A study involving service users and carers in an exploration of their perspectives and experience of respite care.'**

As discussed, I've attached all the documentation for my research including the approval letter from Northumbria University. I would be very grateful if you could give this your consideration. I haven't sent it to  because I thought it would be more appropriate for you as the chair of the ethics committee to involve him and indeed anyone else that you feel should have a look at it. From a service user point of view, I have discussed it and presented information at the service user forum and the carers support group. I have discussed the information sheet with carers at the group and asked them for their opinion on it.  is fully aware of what I'm doing and service users and carers I have spoken to have expressed an interest in the research. I have copied  into this for his information because in all the documentation, I have to say that if anyone is unhappy with what I'm doing, they can contact  as my manager.

As I am behind schedule, I am hoping to start collecting data in September.

If it's any help, I know that  is expected to be at the next Board Meeting on Thursday.

Please let me know if you need any more information or if you have any queries. I will be on holiday from the end of today – back on Tuesday 26<sup>th</sup> August.

Thank you 

 Anna

12<sup>th</sup> September 2008

Anna Wolkowski  
Director of Clinical Services

Dear Anna Wolkowski

This letter is to acknowledge that I have read and approved the research proposal of Mrs. Anna Wolkowski, Director of Clinical Services, titled: Does respite care address the needs of palliative care service users and carers? A study involving service users and carers in an exploration of their perspectives and experience of respite care.

I do not have any problems in performing this study at

Regards,

**Consultant in Palliative Medicine,  
Medical Director,  
Member of the Local Ethical Committee**

## Appendix 7: Extract of anonymised transcript

1 Mc1 (v)  
2 *Right Mary, just forget it's there (tape recorder) Right, you've*  
3 *been on the telly you'll be fine.(Followed on from conversation*  
4 *Mary and Anna had just had)*  
5 A: Mary, just to say this is my first interview with you and the  
6 date is the 21<sup>st</sup> May, and I have just come to talk to you about  
7 your experiences to do with respite care, okay. To start with  
8 Mary, I just need to acknowledge on the tape that, Ron, the  
9 person you were caring for, was going to be involved  
10 originally, you were both going to be involved, but Ron's  
11 passed away since then and I, we've agreed that you would  
12 still like to contribute and erm so we will just be talking to you  
13 about your experiences. Alright?  
14 M: Yes  
15 A: Okay, and don't worry about the tape. So erm could you  
16 just say a little bit to start with Mary about Ron's's illness and  
17 when you were looking after him. And I know that obviously I  
18 know Ron had parkinson's disease. How long did he have  
19 parkinson's disease?  
20 M: Over 27 years.  
21 A: Right, right, 27 years. And did, that's a long time. How  
22 much of that were you actually caring for Ron?  
23 M: When he first got it, diagnosed, he was at work which was  
24 different entirely which meant that he used to come home  
25 often very frustrated because he hadn't been able to cope  
26 with ordinary things like getting his cup of tea. Having to ask  
27 for ask for help, little mundane, ordinary things that we don't  
28 even think about. And erm he did shake a lot in those days  
29 and then had to go into hospital to get medication.  
30 A: Right, and then and so for how long were you actually  
31 physically caring for Ron?  
32 M: He volunteered for an early retirement, unbeknown to me  
33 he suddenly said, 'I am leaving' the specialist wanted him to go  
34 on for another year, he thought it was good but he just  
35 couldn't cope. And it was his decision, his own decision so I let  
36 him make his own decision, it was his disease and he felt his  
37 limitation. And he was unable to go part time, which was a  
38 shame, maybe that would have been a little bit better. But he  
39 was not allowed to do, so he also had to go from A to B which

40 was quite a journey and had to drive himself. They got a bus  
 41 and that was a bit of a help but the bus refused to drop him  
 42 off at the top of his road. And err, because he had  
 43 parkinson's. And I said to him 'tell them you have parkinson's,  
 44 and ask if they will' and he did and the answer was no  
 45 everybody will want the same treatment even if they haven't  
 46 parkinson's they will all want to be dropped off at the end of  
 47 their road.

48 A: Oh dear.

49 M: So we struggled, winter time on the ice and the snow when  
 50 his walking became bad. I think it helped to make him make a  
 51 decision to leave, perhaps before...

52 A: He would have done.

53 M: he normally would have done, because in his head,  
 54 intelligence and his experience in his job, were worth  
 55 something but he was unable to carry on.

56 A: Great shame.

57 M: That was sad really.

58 A: Yes. Caring for Ron, you did have some periods of respite at  
 59 The Oaks and did you have any other periods of respite  
 60 anywhere else Mary?

61 M: Not a lot, just here and there. Erm due because of social  
 62 services coming in to help to dress him and things. They did it,  
 63 through them they would more or less choose where there  
 64 was a place, where I would go. And it usually was when I had  
 65 an operation.

66 A: Right

67 M: I've had a few!

68 A: giggle

69 M: And it was if you do not get your husband into respite, you  
 70 cannot have this operation, and it was an operation often that  
 71 I needed, you know, desperately. And that's how it happened  
 72 really, because necessity, you know. I had to get him away  
 73 somehow, somewhere and therefore I often had to let other  
 74 people choose.

75 A: yeah. And how was that, how was that having to... that  
76 whole feeling that Ron had to go away somewhere, was  
77 that something that you both accepted or was that difficult?

78 M: Sometimes, Ron had to be talked into it by someone else,  
79 by say social service or some medical person, doctor or  
80 anything because you must go you must help Ron. This put  
81 him, it was not very good that, it was almost like emotional  
82 blackmail. Which was not a nice phrase to use really but... and  
83 that worried me, because I sometimes was given 4 places to  
84 choose from erm I did about 5 one afternoon I think,  
85 exhausted me, it upset Ron going round looking at the places  
86 and I am afraid most of them I had to turn down. And I'm not,  
87 I wasn't expecting everything inlaid with gold, but when it  
88 came to a broken bedroom window that you could get your  
89 head through, or sharing a room with someone with  
90 Alzheimer's, I felt that Ron would have been, erm a hazard  
91 to them because of his walking, so it was very stressful,  
92 choosing was stressful.

93 A: mm. That's fine, doesn't matter if we pause, absolutely  
94 fine.

95 M: But there were times when I had to take, you know next to  
96 best really and I thought, well we'll try it. He went to some  
97 places erm perhaps just for one week, erm the caring and the  
98 love was very good but the health, hygiene, safety factors  
99 were not always good I'm afraid. And really quite surprised  
100 me in this present day and age.

101 A:mm

102 M: You know? A stair lift, the belt that you put round the  
103 client/patient was broken etc.

104 A: That is a surprise isn't nowadays.

105 M: And Ron with parkinson's bent over a lot, and he would  
106 have rolled off it. And things like that.

107 A: Once Ron was in respite care, I mean obviously at times you  
108 were having operations and so there was no choice really.

109 M: mm that's right.

110 A: But were you at ease, were you.... How did you feel when  
111 he was in other care? How did it make you feel?

112 M: Well on and off when he did go and I wasn't so ill, and it  
113 was a necessity, erm it was... it took a little time to adjust.

114 A: Yeah

115 M: and by the time you had adjusted, it was time for him to  
116 come home, really. You know you just got yourself organised  
117 and you were finding you were actually getting ready for him  
118 to come back, that there wasn't a lot of time for yourself. To  
119 say I am free, I can do this this, go there. I must see to that for  
120 Ron coming home first and be ready. Jobs that you cannot do  
121 when they are around, I had to get them done and sometimes  
122 a week wasn't long enough even, you know.

123 A: yes

124 M: In another way it was stressful again, but at least you could  
125 relax and do that job. But a strange position to be in at first.

126 A: Would you say that, the primary reason for Ron having  
127 respite was to give you a break, I mean we have just talked a  
128 little bit haven't we about who is it for - the carer or the user

129 M: mm

130 A: Do you think it was to benefit you? I mean like you said you  
131 had to do jobs, it was like you had to do things that you could  
132 do when Ron wasn't here. But the main benefit was for you  
133 do you think or for Ron?

134 O: Sometimes, I hate to say this, I feel judgemental saying this,  
135 but sometimes it wasn't much benefit because more than  
136 once, in fact nearly every time he went in to a nursing home,  
137 mostly when it wasn't The Oaks of course, and it did  
138 happen a couple of times at The Oaks; were rightly so they  
139 would ring me up because there was this and that and the  
140 other that they were not sure about regarding Ron.

141 A: mm, a ha

142 M: Something he was doing, something he needed, some, his  
143 reaction to something and they were not quite sure how to  
144 put it in place.

145 A: Yeah

146 M: It was a specialised thing. One, as an instance was one  
147 nursing home where he, of late, later when he became quite  
148 advanced with this disease. He went a bit, for want of another

149 word, a bit berserk; and doing things which were, quite out of  
 150 character and I think they were quite nervous rightly so. It  
 151 happened to me at home and they got me on the phone. I was  
 152 out of town and I reassured them but I said if he was ill, I  
 153 would make my way straight away to the nursing home, but if  
 154 he wasn't ill and it was just something about a social thing,  
 155 something that had disturbed them, I talked them through it,  
 156 and then they said fine, because I experienced the same at  
 157 home, and it was, they hadn't met it before probably you see.  
 158 So and then they rang me the following day, I kept close  
 159 contact. So that respite, my family said, was not real respite  
 160 for me, it was interrupted respite, but then I just accepted that  
 161 because I thought, you know, who can fully take your place, I  
 162 mean it's a difficult one.

163 A: mm mm

164 M: All the different diseases they have to encounter,

165 A: mm, mm

166 M: My heart went out to them. I knew what they were faced  
 167 with because I had it at home, when I said yes he does this,  
 168 this at home, then they were happy that it was something that  
 169 he did anyway.

170 A: So there is something about them getting to be familiar  
 171 with him really.

172 M: That's right, there were people they hadn't seen him  
 173 before had they..

174 A: yes, yes

175 M: So I had to be ready, to return really, to return home in  
 176 case it got worse you see. So I was a little bit on the ready,  
 177 prepared to return which can't be full respite. Sometimes  
 178 maybe you could go to the same place for respite, all the time  
 179 it can't work and one of the reasons The Oaks worked was  
 180 because he was there each week (in day care) and although  
 181 the nursing care, the nurses qualified nurses in the inpatient  
 182 unit didn't know him quite as well, there was still some  
 183 reference; there was certain people that he did know.

184 A: yes

185 M: It overlapped a bit you see.

186 A: yes



187 M: I think maybe the first time at The Oaks respite could well  
188 have been like that.

189 A: So there is like a getting to know process, really.

190 M: It is difficult respite, I think is a very difficult, erm what's  
191 the word erm package to offer people. I think to give respite  
192 care, when you think of all the different people with all the  
193 different diseases.

194 A: mm

195 M: It is a very hard job.

196

## Appendix 8: Reframing respite care at The Oaks Hospice

### Appendix 8: Reframing respite care at The Oaks Hospice

From the shared learning that the research was based on and has encouraged including listening to service users and carers, the hospice where I work continues to provide and develop creative responses to service users and carers who have expressed a need for respite care. Within these interventions, we are developing a focus on the relationship and promoting a sense of balance in the interventions by providing care and support for the carer as well as the service user ie Family Support Team interventions and complementary therapy for the carer as well as the cared for person. These respite care interventions include:

- Hospice day respite care.
- Within 20 specialist palliative care beds, continuing to provide 2 planned respite care beds. The information booklet begins with the following: "Here at The Oaks Hospice we recognise the importance of respite care".
- Emergency respite care is offered as part of our specialist palliative care provision in recognition of the fact that respite care can often be needed urgently and within this, the needs of the carer or the cared for person may be highly complex and require immediate intervention from the multi disciplinary team.
- 2 family respite care facilities in local holiday parks. Separate from the facilities of the hospice, care is not provided in these facilities but the opportunity for carers and the people they care for and their families to spend time together in peaceful and relaxing environments where there is no charge and usual caring arrangements can be maintained.
- The development of a 12 bedded palliative respite care unit including 2 family respite care suites where service users and carers will be able to stay together and enjoy interventions and quality time together within a palliative care setting.

Shared learning sessions include reflections on referrals for respite care and the development of an audit tool for respite care referrals